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Doctorate in Clinical Psychology: Main Research Portfolio

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Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology Volume 1 of 2

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Doctorate in Clinical Psychology

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Critical Review of Literature

Risk factors and potential treatments for depression in HIV-infected youth in Southern Africa: A systematic review

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Abstract

Depression is common in those with HIV and is associated with lower quality of life, reduced adherence to medication, worse disease progression and higher risk of transmission to other. The majority of HIV-infected youth live in Southern Africa, but research predominantly focuses on adults from Western countries, with limited generalisability across these populations. This review aimed to identify and synthesise research on the risk factors for depression in HIV-infected youth in Southern Africa, and to summarise the available evidence on psychosocial interventions to reduce depression. Papers from 2004–2017 were searched using Embase, PsycNet, PubMed and Scopus. Six studies met inclusion criteria for assessing risk factors, but only three focused exclusively on HIV-infected youth ($n=1,113$; age 9–19 years). Two studies met inclusion criteria for assessing psychosocial interventions, but only one focused exclusively on HIV-infected youth ($n=33$; age 10–13 years). Overall, study quality was low and methodology was heterogeneous, limiting comparability and conclusions. The findings indicate some evidence for demographic factors; social and community support factors; reduced immunosuppression; past traumas/stressors; and psychosocial factors as potential risk factors for depression. Neither of the intervention studies successfully reduced depression, demonstrating a need for low-cost, large scale interventions to be developed and trialled. HIV status should be acknowledged as an important factor in future psychosocial research in Southern Africa.

Keywords: South Africa; mood; HIV; children; adolescents; intervention

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Introduction

It has been consistently demonstrated that rates of depression are considerably higher in HIV-infected adults than in HIV-uninfected adults (Arseniou, Arvaniti, & Samakouri, 2014; Breuer, Myer, Struthers, & Joska, 2011; Freeman, Nkomo, Kafaar, & Kelly, 2008). This finding has been replicated amongst HIV-infected youth aged as young as nine (Elkington et al., 2010; Mellins et al., 2009; Pao et al., 2000). Antiretroviral treatment (ART) for HIV made huge advances in the mid-nineties with the advent of 'triple combination' ART (Palmisano & Vella, 2011). This treatment was rolled out globally, but the drugs only became publically available in South Africa in 2004 (Simelela & Venter, 2014). The effectiveness of ART is now such that HIV is largely viewed as a manageable, chronic condition. Despite this, rates of depression have been found to be higher in youth with HIV than youth with other chronic, life-threatening conditions (Pao et al., 2000).

The association between HIV and depression is bidirectional; while HIV is acknowledged as a risk factor for depression, the presence of depression in those with HIV has been shown to have a serious impact on health-related outcomes. In HIV-infected youth, depression has been associated with decreased adherence to ART (Agwu & Fairlie, 2013; Murphy, Wilson, Durako, Muenz, & Belzer, 2001; Naar-King et al., 2006) and higher risk behaviour (Donenberg & Pao, 2005), thus posing a higher risk of transmission to others. There are further serious consequences if depression continues into adulthood; depression in HIV-infected adults is associated with poorer quality of life (Adewuya et al., 2008; Andrinopoulos et al., 2011; Selvaraj, Ross, Unnikrishnan, & Hegde, 2013), faster disease progression (Ironson et al., 2015; Kopnisky, Stoff, & Rausch, 2004; Leserman, 2003) and, according to some studies, earlier death (Cook et al., 2004; Kopnisky et al., 2004). Early identification and treatment of depression in HIV-infected youth therefore has the potential to improve morbidity and quality of life and reduce transmission to others and mortality.

Southern Africa constitutes the nine countries with the highest adult (aged 15–49) HIV prevalence globally, ranging from 10.3% in Malawi to 27.4% in Swaziland (UNAIDS, 2014). Prevalence data for HIV in youths is less forthcoming, but more than half of all HIV-infected children (aged 0–14) live across these nine countries (UNAIDS, 2013). Despite this region having the highest global prevalence of HIV, a 2011 systematic review of interventions for depression in HIV-infected individuals found that just one of the 90 included studies originated from Southern Africa, with the vast majority of studies ($n=81$) based in Europe and North America (Sherr, Clucas, Harding,

Sibley, & Catalan, 2011). There are several factors that limit the applicability of these findings to youth in Southern Africa. For example, most European/American studies recruited adult male participants with a mean age of 30–40, reflecting the focus on intravenous or homosexual HIV transmission (Sherr et al., 2011). Interventions are therefore unlikely to be developmentally appropriate or take account of relevant systemic contextual differences, such as living with caregivers and attending school. Factors associated with depression—and relevant to treatment—are also likely to differ across these populations. For example, transmission is most commonly vertical in children and via heterosexual contact in adolescents (UNAIDS, 2014; Breuer et al. 2011). This has implications for adjustment to HIV and introduces other factors that may be important, such as having other family members with HIV. In addition, females are disproportionally affected by HIV in Southern Africa; females aged 15–19 in South Africa are eight times more likely to be HIV-infected than males of the same age (South African National AIDS Council Trust, 2015), indicating that gender-related factors may be of importance. Finally, there are several cultural, political and societal differences between Western countries and Southern Africa that have implications for both risk factors for depression and for delivery of interventions. Research directly from Southern Africa is essential for ensuring findings are relevant to Southern African youth and to ensure interventions are viable given resources and the local context. Understanding specific factors associated with depression in this population is important for tailoring interventions for reducing and preventing depression. Previous reviews have identified several potential risk factors for depression in HIV-infected populations, including: biological HIV factors; gender; homelessness; lack of social support; psychosocial factors; history or comorbidity of psychiatric illness; and the perinatal period in HIV-infected women (Arseniou, Arvaniti, & Samakouri, 2014; Nanni, Caruso, Mitchell, Meggiolaro, & Grassi, 2014). However, these reviews were unsystematic—lacking information about the process of study selection, overall study characteristics or the process of data synthesis, as well as lacking critical information about participant characteristics, such as country of origin or age. Breuer et al. (2011) reviewed research in adults in sub-Saharan Africa and identified stage of illness; poor social support; presence of life stressors; and stigma as potential risk factors for depression in HIV-infected, but, again, it is unclear to what degree these findings would generalise to HIV-infected youth in the high prevalence region of Southern Africa.

Developing effective treatments for depression in people living with HIV has far-reaching consequences for improved quality of life, physical health and reduced

transmission to others. Psychological interventions are more consistently effective at treating depression in HIV-infected participants than other interventions, including psychotropic drugs (Sherr et al., 2011) and eliminate potential medical interactions with ART (Cruess et al., 2003), providing a strong rationale for developing effective psychological support for HIV-infected youth. Most HIV-infected youth globally live in Southern Africa, yet current understanding of depression in those living with HIV is based predominantly on adult samples from resource-rich settings. This review aims to synthesise existing research about depression in HIV-infected youth in Southern Africa by answering the follow questions:

1. What factors are associated with depression in HIV-infected youth living in Southern Africa?
2. What does the research tell us about interventions that have been implemented in Southern Africa to reduce depression in HIV-infected youth?

Method

A systematic review was conducted according to PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009).

Search Strategy

Literature searches were carried out in August 2016 using search terms developed in collaboration with a University librarian. Embase, PsycNet, PubMed and Scopus were searched. See Table 1 for Scopus search strategy. Search strategies for the other databases were similar, but ‘all fields’ were searched rather than limiting to ‘title, abstract and keywords’. In addition, database filters were used to restrict the age of participants, in place of using search terms relating to children and adolescents. For the purpose of this review, Southern Africa comprises the following nine countries: Swaziland, Lesotho, Botswana, South Africa, Namibia, Zimbabwe, Zambia, Mozambique and Malawi. These countries have the highest HIV prevalence globally. To identify grey literature, reference lists of included articles were hand-searched and the first 100 references of Google Scholar were searched using the search terms. Database searches were repeated in April 2017 to check for up-to-date studies; 61 new, unique abstracts were identified.

Eligibility Criteria

Studies that used quantitative methodologies to explore the association between depression and other variables in HIV-infected youth were identified. Intervention studies for depression in HIV-infected youth were also identified. Although the primary focus of this review was youth aged <18 years, studies were permitted to include participants as old as 19 years. This decision was taken because demographic data often groups adolescents into 15–19-year-olds (e.g. UNAIDS, 2013) and in Southern Africa it is not uncommon for youth to be aged 19 when completing grade 12 of school (Cosser & du Toit, 2002).

To be included, a study had to: (a) include participants younger than 18 years; (b) include no participants older than 19 (unless data was reported separately for those ≤19 years); (c) report participants' HIV/AIDS status; (d) recruit participants exclusively from Southern Africa; (e) report a measure of depression (either psychiatric interview or validated mood scale); (f) explore variables associated with/predictive of depression AND/OR evaluate impact of a non-medication intervention on depression; (g) be published in English or Afrikaans; (h) be published since 2004.

ART has impacted prognosis and illness trajectory and may have introduced new factors associated with depression, such as medication routines. As this was not rolled out to some Southern African countries (e.g. South Africa, Malawi) until 2004, this was chosen as a publication date cut-off.

Table 1. Scopus search strategy

Field code	Search terms used
Title-Abstract-Keywords	depress* OR "affective disorder*" OR "adjustment disorder*" OR dysthymi* OR mood OR distress AND
Title-Abstract-Keywords	hiv OR aids OR "human immunodeficiency virus" OR "acquired immune deficiency" AND
Title-Abstract-Keywords	botswana* OR batswana OR swazi* OR zimbabwe* OR namibia* OR mozambi* OR lesotho OR basotho OR "south africa*" OR malawi* OR tonga* OR zambia* OR "southern africa*" AND
Title-Abstract-Keywords	child* OR teen* OR young OR pediatric OR paediatric OR adolescen* OR youth* OR juvenile* OR infant* AND
Database filters applied	Publication year > 2003 Language: English or Afrikaans Document type: article, article in press, conference paper

Selection of Studies

Articles returned from database searches were screened for duplicates (CH). Fifty percent of titles and abstracts returned were screened by a second independent rater (NS). Inter-rater agreement was ‘moderate’ (Landis & Koch, 1977) at 82% ($\kappa = 0.48$). To improve consistency in abstract screening, the following rating guidelines were developed:

1. Abstracts were excluded if: (a) there was no mention of HIV, or if the only reference was in the context of ‘area of high HIV prevalence’; (b) participants were referred to as ‘adults’; or (c) participants were clearly recruited from outside of Southern Africa.
2. To be included, abstracts needed to clearly demonstrate at least two of the following three criteria: (a) inclusion of participants <18 years; (b) participants with HIV; (c) a measure of depression mentioned.

Previous disagreements were discussed and resolved using these guidelines. The remaining 50% were then screened independently by the same raters, yielding an ‘almost perfect’ agreement (Landis & Koch, 1977) of 94% ($\kappa = 0.85$). Again, conflicts were discussed and resolved.

Full texts of included articles were then screened by two raters (CH and RR) using the study eligibility criteria. Where studies comprised both eligible samples (≤ 19 years) and non-eligible participants (>19 years), authors were contacted and asked for the data pertaining to those ≤ 19 years. Of the authors contacted ($n=5$), one provided the data requested.

Quality Assessment and Risk of Bias

Quality assessment tools were developed for each of the review questions, which addressed risk of bias within studies. A 16-point quality assessment tool was developed for cross-sectional and longitudinal studies, informed by previously used tools (Herzog et al., 2013; Matcham, Rayner, Steer, & Hotopf, 2013). A second 17-point tool was developed for the assessment of intervention studies, which incorporated additional elements for intervention studies (Downs & Black, 1998). See Appendix A for both quality assessment tools.

Two independent raters (CH and HW) assessed the quality of papers using the tools. Quality of papers was assessed according to the questions posed in this review. Discrepancies were minimal and were resolved by a third rater (ML).

Data Extraction and Synthesis

The small number of eligible studies and heterogeneity of risk factors studied precluded a meta-analysis. Data extraction was carried out using a purpose-designed form. Where data relevant to the review questions were not reported separately, authors were contacted ($n=3$); none provided the data. Data was presented using narrative synthesis for: (a) risk factors associated with depression; and (b) effectiveness of interventions for reducing depression. For synthesis of risk variables associated with depression, variables were grouped into categories representing conceptually comparable constructs.

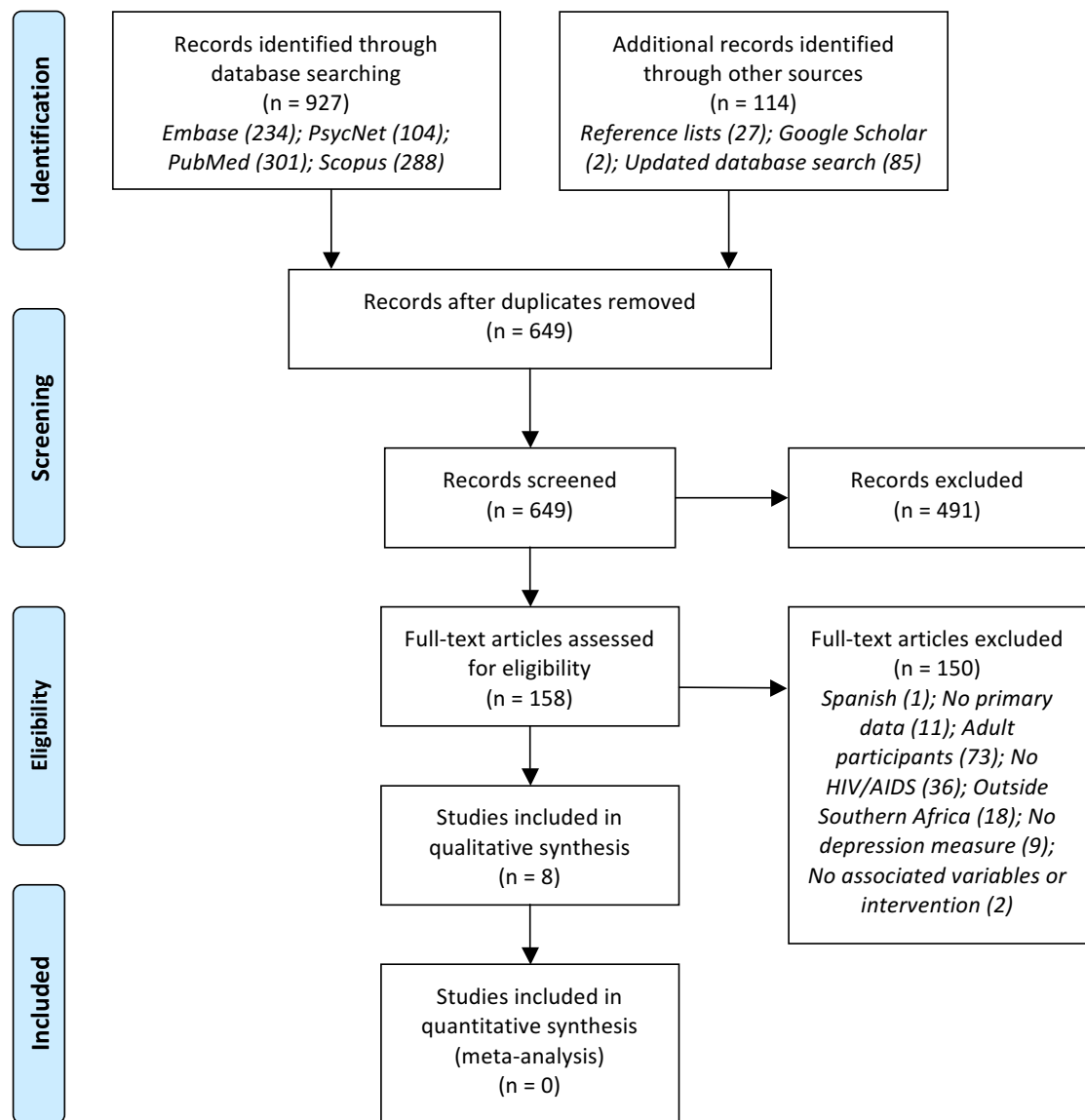


Figure 1. PRISMA flowchart of study selection (Moher et al., 2009).

Results

A total of six studies met the inclusion criteria for examining risk factors for depression in HIV-infected youth in Southern Africa. A further two studies met the inclusion criteria for examining effectiveness of interventions for reducing depression in HIV-infected youth in Southern Africa. See Figure 1 for flow chart of study selection.

Risk Factors Associated with Depression

Study characteristics and quality. Six studies were included, comprising a total of 1,271 HIV-infected youth (aged 4–19 years). Of the six studies, three comprised HIV-infected participants exclusively (Bhana et al., 2016; Kim et al., 2015; Woollett, Cluver, Bandeira, & Brahmabhatt, 2017). Participants in Målqvist, Clarke, Matsebula, Bergman and Tomlinson's (2016) study comprised both adults and adolescents (age ≥ 14), only some of whom were HIV-infected ($n=412$). However, the authors provided their dataset when contacted, allowing separate analysis for eligible participants ($n=31$) and therefore inclusion in this review. The remaining two papers (Sherr, Croome, Clucas, & Brown, 2014; Skeen, Macedo, Tomlinson, Hensels, & Sherr, 2016) contained exclusively child and adolescent participants (ages 4–19), but data was not consistently reported separately for HIV-infected participants. Authors were contacted for this data, but this was not provided, strongly limiting the conclusions that can be drawn from these studies. As a result, analysis is largely based on a sample of 1,113 HIV-infected youth aged 9–19 years.

None of the included studies provided justification or power analyses for their sample sizes, but the three studies that focused solely on HIV-infected youth provided sample sizes of 177 (Bhana et al., 2016); 343 (Woollett et al., 2017); and 562 (Kim et al., 2015). These studies also recruited from specialist HIV clinics using convenience sampling. While this provides a feasible recruitment method for researchers, and is an effective way of verifying the HIV status of participants, convenience sampling is associated with a higher risk of bias than consecutive or random sampling (Schuster & Powers, 2005). In addition, recruiting from HIV clinics is likely to exclude youth who have not undergone testing, choose not to use HIV services, or are unable to do so. The remaining three studies used the more robust method of consecutive sampling, but relied on self-report of HIV status (Målqvist et al., 2016; Sherr et al., 2014; Skeen et al., 2016) and did not report data separately for HIV-infected participants. Although Målqvist et al. (2016) provided their dataset on request, only 31 participants were

eligible for inclusion in this review reducing the power of the analysis and generalisability of the results.

Studies recruited from South Africa (Bhana et al., 2016; Sherr et al., 2014; Skeen et al., 2016; Woollett et al., 2017); Malawi (Kim et al., 2015; Skeen et al., 2016); and Swaziland (Målqvist et al., 2016). Two studies focused on sub-populations of HIV-infected youths: perinatally-infected youths (excluding those infected via horizontal transmission; Bhana et al., 2016) and pregnant females (Målqvist et al., 2016).

Only one study used a clinical interview (Child Depression Rating Scale-Revised; CDRS-R) to measure depression (Kim et al., 2015). While clinical interviews are deemed more methodologically rigorous than screening tools, clinical interviews too have their limitations. As outlined by Kim et al. (2014), although the CDRS-R has demonstrated excellent psychometrics in Europe, America and Asia, the lack of child mental health research and public sector resource in Southern Africa means there is a lack of validation for the CDRS-R in these countries. This is of particular significance given the cultural adaptation of measures that is required (Kim et al. 2014). Kim et al. (2015) used the Beck Depression Inventory-II (BDI-II) screening tool in addition to clinical interview. The remaining five studies used screening tools only: one used the Edinburgh Postnatal Depression Scale (EPDS; Målqvist et al., 2016) and the other four used the Child Depression Inventory Short Form (CDI-S; Bhana et al., 2016; Sherr et al., 2014; Skeen et al., 2016; Woollett et al., 2017). The BDI-II and EPDS have both been validated for use in Southern Africa and psychometrics are reported (Chibanda et al., 2010; Kim et al., 2014). Although the CDI-S has been used in Southern Africa, it has not been adequately validated; whilst Snider and Dawes (2006) addressed the wording of items, no psychometrics were provided for Southern African populations. Studies mostly assessed risk factors for higher depressive symptoms (by use of total score on screening tools) rather than presence of clinical depression (Bhana et al., 2016; Kim et al., 2015; Sherr et al., 2014; Skeen et al., 2016; Woollett et al., 2017). Woollett et al. (2017) conducted a second analysis using presence of >50% of symptoms as an outcome (defined by the authors as scoring one or two, on five or more items), which the authors classified an increased risk of depression. Målqvist et al. (2016) used a cut-off of ≥ 13 on the EPDS to compare depressed and non-depressed participants.

There was considerable heterogeneity in the variables measured, as well as method of measurement, limiting comparability across studies. Målqvist et al. (2016) focused solely on demographic characteristics of participants in relation to depression. Kim et al. (2015) additionally measured psychosocial variables, but no description of

the questionnaires used was provided. The remaining papers measured more complex variables in addition to demographics and all used a combination of measurement scales validated for use in Southern Africa and tools not validated, but described or available to the reader (see Table 3).

Overall, quality of included studies was generally poor with total quality assessment scores ranging from 3–8 across the six studies (possible range 0–16). Kim et al.'s (2015) study was rated as the most methodologically robust, with a large sample size, clinically-verified HIV status and use of clinical interview to assess depression. Despite this, reporting of their analyses and results was unclear, making it difficult to draw confident conclusions. In addition, description of questionnaires used to measure risk factors was poor.

Demographic factors.

Gender. Two studies assessed the association between gender and depression in HIV-infected participants. Being female was associated with higher depressive symptoms on both the BDI-II ($p=0.002$; Kim et al., 2015) and CDI-S ($p<.001$; Woollett et al., 2017). However, gender was not significantly associated with depression when determined using clinical interview (Kim et al., 2015), nor when defined as experiencing >50% of symptoms on the CDI-S, although this approached significance ($RR=1.69$, $p=.06$; Woollett et al. 2017). Although Bhana et al. (2016) controlled for gender in their analysis, they did not report the direct effect of gender on depression.

Age. Two studies measured the association between age and depression, with one finding evidence of an association with older age. Kim et al. (2015) included participants aged 12–18 years and found depression to be associated with older age when using cut-off on the CDRS-R ($p=.004$). When measuring depressive symptoms using the BDI-II there was no direct effect of age; however, there were significant interactions between age and satisfaction with physical appearance, and age and height-for-age z-score. More specifically, older participants who were more dissatisfied with their appearance ($p=.03$), or who had a lower height-for-age z-score ($p=.007$) had higher BDI-II scores. Woollett et al. (2017) included participants aged 13–19 years and found no association between age and CDI-S score or risk of being symptomatic. Bhana et al. (2016) controlled for age in their analysis, but no direct analysis of age was on CDI-S score was reported. It was not possible to analyse the association between depression and age using Målqvist et al.'s (2016) dataset, as the age range of eligible participants was too small at 16–19 years.

Ethnicity. Woollett et al. (2017) was the only study to report measuring ethnicity as a demographic variable. This was not reported as a significant variable in relation to depression.

Schooling. Two studies measured schooling variables, with contrasting findings. While Kim et al. (2015) found fewer years of schooling (categorised by grade) to be associated with both higher BDI-II score ($p=.0005$) and clinical depression using the CDRS-R ($p=.005$), Woollett et al. (2017) found that neither current grade, nor highest grade achieved were associated with CDI-S score or risk of being symptomatic. Having failed a school term/class was also associated with higher BDI-II score ($p=.01$ adjusted; Kim et al., 2015).

Household income. Three studies measured household income, with no association found with depression. Variables measured were: presence of a job or pension (Bhana et al., 2016), estimated combined income (Kim et al., 2015) and caregiver receipt of grants for children (Bhana et al., 2016; Woollett et al., 2017).

Caregiver demographics. Two studies considered a range of caregiver variables in relation to depression in youth. Only education of the primary caregiver was associated with depressive symptoms, with lower education (defined as eighth grade or less) predicting higher CDI-S scores ($p=.01$; Bhana et al., 2016). Non-significant variables were caregiver employment, caregiver depression (measured using screening tools), caregiver HIV status (Bhana et al., 2016); primary caregiver type (i.e. single parent; both parents; aunt/uncle; grandparent/other); maternal employment status or death; and whether there had been a change in caregiver (Kim et al., 2015).

Food security. Three studies looked at measures of food security, with some evidence of an association between less food security and depression. Woollett et al. (2017) found that more 'days hungry' was significantly associated with higher CDI-S score ($p<.001$), but this was not a significant predictor of experiencing $>50\%$ of symptoms. Bhana et al. (2016) found higher CDI-S score was associated with less food security ($p=.029$), although this association did not remain significant after controlling for age, gender and study indicator. Analysis of eligible participants ($n=28$) from Målqvist et al.'s (2016) dataset found that, in contrast to the overall dataset, there was no significant association between depression and their three measures of food security (see Appendix B).

Other household variables. A range of other household variables were considered across four studies, with most found to have no association with depression. Bhana et al. (2016) found higher CDI-S scores were associated with higher household

density ($p=.041$), although this did not remain significant when controlling for age, gender and study indicator. Woollett et al. (2017) found that youth *not* looking after a sick person in the home was significantly associated with higher depression score ($p=.04$). This was not a significant predictor for experiencing >50% of symptoms. Analysis of Målvist et al.'s (2016) dataset demonstrated a significant association between being a homeowner/living with parents (rather than renting) and depression ($p=.047$); whilst this replicated findings from the overall dataset, the eligible sample was very small ($n=22$), with only one participant owning their home. There was also a trend towards an association between water source and depression ($n=30$), with those sourcing household water from surface more likely to experience depression than those sourcing water from communal taps or on-site taps ($p=.058$); this association was not found in the overall dataset. Sharing a toilet was not found to be associated with presence of depression in HIV-infected participants aged ≤ 19 ($n=23$), although this was found to be significant in the overall sample.

Other variables not found to be associated with depression include whether the young person's caregiver is living in their own home (Bhana et al., 2016); location of home; and travel time between home and clinic (Kim et al., 2015); household composition; formal or informal housing; and looking after younger siblings at home (Woollett et al., 2017).

Social and community support.

Disclosure. Two studies looked at disclosure in relation to depression, with some mixed findings. Kim et al. (2015) found that participants who were aware of their HIV status and had disclosed it to others had lower BDI-II scores than those who had not disclosed to others, or who were not aware of their HIV status ($p=.02$). While Woollett et al. (2017) found that participants who knew their HIV status had significantly lower CDI-S scores than those who did not know ($p<.001$), they found no association between disclosure of their status to others (27% of the sample) and depression.

Other social and community variables. Several social and community variables were found to be significantly associated with depression in HIV-infected participants across three studies. Bhana et al. (2016) measured caregiver supervision with youth-rated and caregiver-rated questionnaires addressing rules, how caregivers keep track of their child's whereabouts, and how often children are left in charge of the home. Lower youth-rated caregiver supervision was associated with higher depression ($p=.01$), as was

lower likelihood of youths seeking social support ($p=.003$). Both associations remained significant when controlling for age and gender ($p=.012$ and $p=.002$ respectively).

Not having a safe place in the community was significantly associated with experiencing $>50\%$ of symptoms on the CDI-S ($p<.001$; Woollett et al. 2017). Surprisingly, youth who reported receiving praise at home; getting the same things as other children in the home; and feeling like they belonged in the family they were being raised in experienced higher CDI-S scores than those who did not (all $p<.001$; Woollett et al., 2017). Kim et al. (2015) asked participants if they had an experience of being in a romantic relationship that did not involve sex. Those with a current or past boyfriend/girlfriend had higher BDI-II scores than those who had never had a boyfriend/girlfriend ($p=.002$).

Health variables. Several health variables were assessed in relation to depression by two studies. Immunosuppression classification (based on CD4) was the only significant variable found, with more severe classification predicting higher BDI-II scores ($p=.0009$), but not depression according to the CDRS-R (Kim et al., 2015). All other bio-clinical parameters assessed by Kim et al. (2015) were not significantly associated with depression. This included: ART use (93.6% of the sample were on ART); efavirenz-based regimen; second-line ART; history of tuberculosis; most recent CD4 count; current nutritional status; alcohol use and hospital admission in the past year. Woollett et al. (2017) also found that history of tuberculosis and being hospitalised were not associated with depression.

Past trauma/stressors.

Violence and abuse. Two studies looked at measures of violence in relation to depression, with mixed findings. While Kim et al. (2015) found no association between depression and experience of forced sex, physical abuse or witnessing physical abuse in the home, Woollett et al. (2017) found experience of forced sex was significantly associated with relative risk of experiencing $>50\%$ of CDI-S symptoms ($p=.02$). Furthermore, specific items from measures developed for use in South Africa were analysed as predictors and it was found that history of being inappropriately touched ($p=.01$), being hit ($p<.001$) and feeling unsafe at home ($p<.001$) were all associated with higher CDI-S score, as well as relative risk of experiencing $>50\%$ of symptoms ($p=.01$; $p=.02$ and $p<.001$ respectively). Peer violence inside and outside of school was also

significant in both the bivariate analyses ($p=.01$) and relative risk analysis ($p=.04$).

Having witnessed somebody being stabbed or shot was not found to be associated with depression.

Bereavement. Two studies assessed bereavement as a variable, with contradictory findings. Kim et al. (2015) found that a death in the family/household was related to higher BDI-II score ($p=.01$), whilst Woollett et al. (2017) found that neither a significant bereavement, nor orphanhood status, were not associated with depression.

Bullying. Only one study looked at the relationship between depression and bullying (Kim et al., 2015). Being bullied for taking medication was found to be associated with depression when measured by both the BDI-II and CDRS-R (both $p<.0001$). Being bullied for appearance was not found to be related to depression.

Psychosocial factors. Three studies looked at varied psychosocial factors in relation to depression. Woollett et al. (2017) found that suicidality ($p<.001$); feeling unable to one's their future ($p=.04$) and not having dreams for one's future ($p<.001$) were all relative risks for experiencing $>50\%$ of symptoms on the CDI-S. These variables were also associated with overall CDI-S score, as was higher score on a measure of anxiety (all $p<.001$). Higher score on the Child PTSD Checklist, was not significantly associated with depression.

Bhana et al. (2016) found lower self-concept (as measured using a scale validated for use in Southern Africa) was associated with higher score on the CDI-S ($p<.001$), as was higher internal stigma ($p=.027$). Two of the ten coping styles measured by the Kidcope were found to be associated higher CDI-S score: social withdrawal ($p=.022$) and resignation ($p=.036$), although this was only assessed in the pilot-study participants ($n=66$).

Kim et al. (2015) found that satisfaction with appearance was not independently associated with depression, but there was an interaction effect with age, as previously described.

Potential Treatments for Depression

Study characteristics and quality. Only two studies identified tested psychosocial interventions for depression in HIV-infected youth in Southern Africa. One included HIV-infected participants exclusively ($n=59$ completed follow up; Bhana et al., 2014); the other included only a small proportion of participants who self-reported to be

HIV-infected ($n=36$; Mueller, Alie, Jonas, Brown, & Sherr, 2011). A request was made to the authors of this study, but it was not possible to obtain data for the HIV-infected participants. As a result, the conclusions that can be drawn from this study are very limited.

Both studies used the CDI-S as the measure of depression. While Bhana et al.'s (2014) sample (age 10–13) were clinically-verified as being HIV-infected, Mueller et al. (2011) relied on self-report from their participants (age 8–18). Bhana et al.'s (2014) pilot-RCT randomly allocated participants to treatment or control groups, whereas Mueller et al. (2011) used arbitrary allocation, which resulted in a high number of significant differences in between-group characteristics. In addition, Mueller et al. (2011) used a quasi-experimental design with outcome measurement at only one time point, whereas Bhana et al. (2014) used a pre-post design. Bhana et al.'s (2014) youth-caregiver CHAMP-adapted intervention was described, with curriculum provided. Mueller et al.'s (2011) MAD About Art intervention did not provide an adequate description. Bhana et al. (2014) scored 8 using the quality assessment tool (possible range 0-17), while Mueller et al. (2011) was rated very poor quality with a score of 2.

Findings. Bhana et al. (2014) used generalised linear models to compare intervention and control groups over time, which accounted for the effect of repeated measures. Mueller et al. (2011) used linear regression to measure association between intervention attendance and depression in the whole sample, regardless of HIV status. Neither intervention was found to have a significant effect on depression.

Table 2. Quality assessment and risk of bias in papers examining risk factors for depression

Study	Recruitment	Eligibility criteria	Sample size justified?	Sample size	Participation rate	Criteria for depression	Criteria for HIV	Confounding	Statistical analysis	Reporting of results	Total score
(Bhana et al., 2016)	Convenience sampling	Specified (+)	Not justified	177 (+)	Not reported	Screening tool not validated for use in Southern Africa	Clinically verified (+)	Adjusted for age, gender, study indicator (+)	No correction for multiple comparisons. Adequate (+)	No <i>M</i> , range or <i>SD</i> for depression score. No CI for regression.	+++++
(Kim et al., 2015)	Convenience sampling	Not specified	Not justified	562 (++)	Reported. Over 75% (++)	Clinical interview and screening tool validated for use in Southern Africa (++)	Clinically verified (+)	Adjusted for age and gender (+)	Not clearly described	Reporting unclear	+++++ +++
(Mälqvist et al., 2016)	Consecutive sampling (++)	Not specified	Not justified	31 with HIV	Not reported	Screening tool validated for use in Southern Africa (+)	Self-report	N/A	Did not analyse HIV sample separately ^a	<i>M</i> , range and <i>SD</i> for depression score reported. OR and CI reported (+)	++++ 4
(Sherr et al., 2014)	Consecutive sampling (++)	Specified (+)	Not justified	23 with HIV	Reported. Over 75% (++)	Screening tool not validated for use in Southern Africa ^b	Self-report	N/A (no group differences in age, gender etc.)	Did not analyse HIV sample separately	Did not analyse HIV participants separately	+++++ 5
(Skeen et al., 2016)	Consecutive sampling (++)	Not specified	Not justified	135 with HIV	Reported. Over 75% (++)	Screening tool not validated for use in Southern Africa	Carer-report	Adjusted for country, age, gender and HIV status (+)	Did not analyse HIV sample separately	Did not analyse HIV participants separately	+++++ 5
(Woollett et al., 2017)	Convenience sampling	Not specified	Not justified	343 (+)	Not reported	Screening tool not validated for use in Southern Africa	Clinically verified (+)	No adjustment for confounding variables	No correction for multiple comparisons. Adequate (+)	No <i>M</i> , range or <i>SD</i> for depression score. Reporting unclear.	+++ 3

M, mean; *SD*, standard deviation; CI, confidence intervals; OR, odds ratio

^a Study itself did not analyse HIV-infected sample separately, but authors provided data to allow analysis for this review. Analysis available in Appendix B.

^b While Sherr et al. (2014) state the CDI-S is validated for use in Southern Africa, the authors of this review did not consider validation to be adequate

Table 3. Measures used in studies examining risk factors for depression

Study	Using tool validated for use in South Africa	Tool not validated in South Africa but available or described	No description of measurement tool
(Bhana et al., 2016)	SDQ (parent version) CES-D (caregiver depression) Tennessee Self-Concept Scale 2	BDI-II (caregiver depression) Caregiver supervision Youth and caregiver communication: frequency and comfort HIV/AIDS related stigma Kidcope	Caregiver demographics
(Kim et al., 2015)			Sociodemographic behavioural questionnaire
(Målvist et al., 2016)		Demographics collected only	
(Sherr et al., 2014)	Self Efficacy Questionnaire for Children SDQ Social connection scale	Sociodemographics Rosenberg Self Esteem Adapted Community, Maltreatment, Exploitation and Discrimination scale ^a Adapted Parent-Child Conflict Tactics Scale ^b Adapted Social and Health Assessment ^c	
(Skeen et al., 2016)	SDQ	Trauma Symptom Checklist for Children Rosenberg Self Esteem Items from the Social and Health Assessment Items from UNICEF survey tool Items adapted from the Parent-Child Conflict Tactics Scale ^d Items adapted from International Society for the Prevention of Child Abuse and Neglect screening tools ^e	Demographics
(Woollett et al., 2017)	Child PTSD checklist 28-item RCMAS (abbreviated version) ^f	MINI international psychiatric interview South African National Food Consumption Survey UNICEF scales for sub-Saharan Africa Child exposure to community violence checklist Peer victimization scale National survey of HIV and risk behaviour amongst young South Africans and the South African demographic and health survey Future outlook	

SDQ, strengths and difficulties questionnaire; CES-D, centre for epidemiologic studies depression; BDI-II, Beck depression inventory-II; RCMAS, revised child manifestation of anxiety scale.

^{a, b, c} Authors added items to these scales.

^{d, e} Adaptations made but not fully described, although original scales are available.

^f 28-item version validated. It is unclear if the authors abbreviated this further, and if so, how this may have affected validity.

Table 4. Data extraction and risk of bias from studies examining risk factors for depression in HIV-infected youth

Study	Sample	Design	Key measures	Associated with depression	Not associated with depression
(Bhana et al., 2016)	Perinatally-infected HIV+ children and carer dyads recruited for VUKA family program ($N=177$) Age: 9–14 ($M=11.68$; $SD=1.42$) 49% female Country: South Africa	Cross-sectional, using baseline data from RCT and pilot-RCT	HIV status Recruited from paediatric HIV clinics and public hospitals. Depression measure CDI-S; $\alpha=.30$ (total score used as variable)	Higher CDI-S score associated with: 1. lower caregiver education ($\beta = -.412, p=.010$) ^a 2. higher household density ($\beta = 0.092, p=.041$) 3. less food security (ie. caregiver less reported hunger in the past month) ($\beta = 0.254, p=.029$) 4. lower self-concept ($\beta = -.076, p<.001$) ^a 5. higher internal stigma ($\beta = 0.655, p=.027$) ^a 6. lower levels caregiver supervision ($\beta = -1.667, p<.001$) ^a 7. lower likelihood of seeking social support ($\beta = 0.429, p=.003$) ^a 8. use of social withdrawal as coping method ($\beta = 1.297, p=.022$) 9. use of resignation as coping method ($\beta = 1.156, p=.036$) ^a	1. caregiver living in own place 2. caregiver receiving any grants for child 3. household income 4. caregiver employment 5. caregiver HIV status 6. caregiver depression (measured by BDI-II or CES-D)
(Kim et al., 2015)	HIV+ adolescents ($N=562$) Age: 12–18 ($M=14.5$; $SD=2$) 56% female Country: Malawi	Cross-sectional	HIV status Recruited from HIV clinics Depression measure Chichewa version of BDI-II; $\alpha=N/A$ (total score used as variable) CDRS-R interview (depression defined as score ≥ 55)	Higher BDI-II score associated with: 1. female gender ($\beta = 2.13, p=.002$) 2. fewer years of schooling ($\beta = 3.84, p=.0005$) 3. death in the family/household ($\beta = -1.77, p=.01$) 4. failing a school term/class ($\beta = -1.46, p=.003$) 5. being bullied for taking medications ($\beta = 5.31, p<.0001$) 6. experience of a romantic relationship ($\beta = -2.38, p=.002$) 7. not disclosing and sharing HIV status ($\beta = -1.83, p=.02$) 8. worse level of immunosuppression ($\beta = -2.58, p=.0009$) 9. older age*low satisfaction with appearance ($\beta = -.93, p=.03$) 10. older age*lower height-for-age z score ($\beta = -20.39, p=.007$) Presence of depression (CDRS-R) associated with: 1. age ($\beta = 1.23, p=.004$) 2. fewer years of schooling ($\beta = 3.30, p=.005$) 3. being bullied for taking medications ($\beta = 4.20, p<.0001$)	1. school grade 2. family income 3. location of home 4. time it takes from clinic to home 5. primary caregiver type 6. maternal death or employment status 7. change in caregiver 8. experience of forced sex, physical abuse, or witnessed physical violence in home 9. being bullied for appearance 10. hospital admission in last year 11. satisfaction with physical appearance 12. use of alcohol in past 30 days 13. age of HIV disclosure 14. whether on ART or not 15. history of TB treatment 16. initial WHO stage 17. most recent CD4 count 18. nutritional status
(Målqvist et al., 2016)	Pregnant women (regardless of HIV status)	Cross-sectional	HIV status Self-report Depression measure	Presence of depression (≥ 13 on EPDS) associated with: 1. being a home-owner or living in the parental homestead (compared with being a tenant; $p=.047$) Trend towards:	1. mother's education 2. marital status 3. employment 4. sharing toilet 5. cut size of meals

<i>Data obtained from lead author for adolescent HIV+ participants: (n= 31)</i>		EPDS; $\alpha=N/A$ (depression defined as score ≥ 13)	1. household water sourced from surface (compared with communal tap or tap on site; $p=.058$, $SR =2.2$)	6. not eat for whole day 7. cut meals for children
Age: 14–19, ($M=17.88$; $SD=1.15$) 100% female Country: Swaziland				
(Sherr et al., 2014)	Children attending local township school and community centre (regardless of HIV status)	Between groups comparison (single orphan vs. double orphan vs. no parental death) on a range of child outcomes	HIV status Self-report	It was not possible to obtain the data for the HIV+ participants separately.
	Overall sample ($N=381$) Age: (8–19, ($M=12.8$, $SD=2.3$) 51% females Country: South Africa		Depression measure CDI-S; $\alpha=.65$ (total score used as variable)	
	Reported being HIV+ ($n=23$)			
(Skeen et al., 2016)	Children attending community-based organisations (regardless of HIV status)	Longitudinal, with cross-sectional data at baseline	HIV status Carer report	It was not possible to obtain the data for the HIV+ participants separately.
	Overall sample ($N=989$) Age: 4–13 ($M=8.9$; $SD=N/A$) Country: South Africa and Malawi		Depression measure CDI-S; $\alpha=N/A$ (total score used as variable)	Reporting being HIV+ was not significantly associated with depressive symptom scores. Exposure to interpersonal violence in the home was significantly associated with higher depression symptom score ($p \leq .0001$). This remained significant after controlling for HIV status ($p < .0001$).
	Reported to be HIV+ ($n=135$)			

(Woollett et al., 2017)	HIV+ adolescents (n = 343) Age: 13–19 (M=16; SD= N/A) 52% female Country: South Africa	Cross-sectional	HIV status Recruited from paediatric HIV clinics Depression measure CDI-S; $\alpha = .70$; (total score used as variable AND symptomatic defined as experiencing >50% of symptoms)	1. higher depressive score (CDI-S) associated with: 2. more days hungry ($p<.001$) 3. higher anxiety score ($p<.001$) 4. higher peer violence score ($p<.001$) 5. higher PTSD score ($p<.001$) 6. female gender ($p<.001$) 7. not looking after sick person in the home ($p=.04$) 8. feeling they belong ($p<.001$) 9. gets praise ($p<.001$) 10. get same things as other children in home ($p<.001$) 11. suicidality ($p<.001$) 12. peer violence inside and outside of school ($p=.01$) 13. experienced violence: inappropriate touch ($p=.01$) 14. experienced violence: been hit ($p<.001$) 15. experienced violence: don't feel safe at home ($p<.001$) 16. not know their status ($p<.001$) 17. don't feel control future ($p<.001$) 18. don't have dream ($p<.001$) 19. Associated with presence of >50% of symptoms: 20. been hit ($p=.02$) 21. been inappropriately touched ($p=.01$) 22. do not feel like they control their future ($p=.04$) 23. do not feel safe at home ($p<.001$) 24. do not have a dream ($p<.001$) 25. do not have a safe place in the community ($p<.001$) 26. have experienced forced sex ($p=.02$) 27. experienced peer violence outside of school ($p=.01$) or in and outside school ($p=.04$) 28. any form of suicidality ($p<.001$)	1. age 2. ethnicity 3. household composition 4. formal/informal housing 5. grade 6. highest school grade achieved 7. orphanhood status 8. looks after young children in home 9. has had sex 10. seen someone shot 11. seen someone stabbed 12. receiving grants 13. has had TB 14. significant bereavement (parent, sibling, primary carer) 15. knowing how contracted HIV 16. disclosed status to others 17. age by sex 18. times things stolen 19. number of losses 20. years since loss 21. often drink
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Note. Mälqvist et al.'s (2016) results derived from analysis of dataset provided by authors. See Appendix B for full analysis.

CDI-S, child depression inventory short form; BDI-II, Beck depression inventory-II; CDRS-R, children's depression scale revised; EPDS, Edinburgh postnatal depression scale; SR, adjusted standardised residual

^a remained significant after adjusting for age, gender and study indication (pilot or RCT)

Table 5. Quality assessment and risk of bias in studies examining interventions for depression

Study	Recruitment	Eligibility criteria	Sample size justified?	Participation rate	Criteria for depression	Criteria for HIV	Allocation to condition	Description of intervention	Assessment of outcome	Confounding	Follow up	Statistical analysis	Reporting of results	Total score
(Bhana et al., 2014)	Convenience	Specified (+)	Not justified	Reported. Over 75% (+)	Screening tool not validated for use in Southern Africa	Clinically verified (+)	Random (+)	Clearly described (+)	Unclear	None	Reported (+)	Appropriate and robust (++)	No SD or CI in group comparison	++++ ++++ 8
(Mueller et al., 2011)	Convenience	Specified (+)	Not justified	Reported. Comparison group less than 75%	Screening tool not validated for use in Southern Africa ^a	Self-report	Non-random	Not clearly described	Not blind	Adjusted for age, gender and other variables (+)	Not reported	Did not analyse sample separately	Did not report HIV data separately	++ 2

SD, standard deviation; CI, confidence intervals

^a As above, it was deemed by the authors of this review that the CDI-S has not been adequately validated for use in Southern Africa

Table 6. Data extraction from studies examining interventions for depression

Study	Sample	Design	Key measures	Intervention	Effect of Intervention
(Bhana et al., 2014)	65 families (Intervention: $n=33$; Control: $n=32$); 59 families completed follow-up	Pilot-RCT	HIV status Recruited from clinics. All children enrolled in HIV care and aware of their HIV+ status.	VUKA family program: culturally-adapted CHAMP model intervention 6 sessions over 3-month period Delivered by lay counsellors, supervised by psychologist	No significant effect of VUKA on youth depression ($\beta = -.736$, $p = .417$)
	Age: 10–13 ($M=11.57$; $SD=1.16$)			HIV+ youth and primary caregivers in group setting Culturally-tailored cartoon storyline to deliver information, facilitate discussion and problem solving. Session topics included: (a) AIDS-related loss and bereavement; (b) HIV transmission and treatment knowledge; (c) Disclosure of HIV status to others; (d) Youth identity, acceptance and coping with HIV; (e) Adherence to medical treatment; (f) Stigma and discrimination; (g) Caregiver-child communication, particularly on sensitive topics such as puberty and HIV; (h) Puberty; (i) Identifying and developing strategies to keep children safe in high-risk situations where sexual behaviour and drug use are possible; and (j) Social support	
	100% of participants Black of Zulu ethnicity		Depression measure CDI-S; $\alpha=.54$ (total score used as variable)		
	Country: South Africa				
(Mueller et al., 2011)	Children attending school-based programme regardless of HIV status. Overall sample $n=297$ (Intervention: $n=177$; Control: $n=120$) Age: 8–18 ($M=12.2$; $SD=N/A$) Reported being HIV+ $n=36$ (Intervention: $n=20$; Control: $n=16$)	Quasi-experimental, cross-sectional, post-intervention design	HIV status Self-report Depression measure CDI-S; $\alpha=.66$ (total score used as variable)	MAD ('Make A Difference') About Art 50+ sessions for 6 months Delivered by trained and supervised 'youth ambassadors' Activities include children creating 'hero' books about their own life journey and group HIV education activities focused on self-advocacy and empowerment.	It was not possible to obtain the data for HIV+ participants separately. In the overall sample, no significant difference found in post-intervention depression score between intervention and control group
CDI, Child depression inventory					
	Country: South Africa				

Discussion

This review sought to identify risk factors for depression in HIV-infected youth in Southern Africa and evaluate potential psychosocial interventions.

Six studies were identified that collected data pertaining to risk factors, but qualitative synthesis was based largely on three studies that explored this question explicitly and reported data separately for HIV-infected participants.

Demographic Factors

This review found female gender to be associated with higher depressive symptoms, but not with presence of depression when using cut-offs. Female gender has been identified as a risk factor for depression in HIV-infected adults in Southern Africa (Olley, Seedat, Nei, & Stein, 2004), as well as in the general population, including in Southern Africa (Bromet et al., 2011; Nduna, Jewkes, Dunkle, Jama Shai, & Colman, 2013; Salk, Hyde, & Abramson, 2017; Tomlinson, Grimsrud, Stein, Williams, & Myer, 2009). A recent meta-analysis found that this gender difference is not present in young childhood, but starts emerging at around age 12 in the general population (Salk et al., 2017). The current review found some evidence of an association between depression and older age in participants age 12–19, but no gender and age interactions were reported. As the sample in this review was limited to those aged 12–19, future research could benefit from broadening the age range to explore this interaction further. This could also allow risk factors to be categorised by age range and suitable interventions tailored accordingly.

The findings in this review provide some evidence for an association between food insecurity and depression, but no association between household income and depression. The fact that food security was not significantly associated with depression in Bhana et al.'s (2015) study when controlling for age, gender and study indicator may be because the two samples (pilot and main RCT) were recruited from different locations and differed significantly in the number of individuals experiencing food insecurity. Southern African studies of youth where HIV-status has not been assessed have also found food insecurity to be a strong predictor of depression (Bachman DeSilva et al., 2012; Collishaw, Gardner, Aber, & Cluver, 2016). American studies that have made distinctions between food insecurity and poverty, have found only the former to be associated with depression in youth (Alaimo, Olson, & Frongillo, 2002; Slopen, Fitzmaurice, Williams, & Gilman, 2010).

In this review lower level of schooling was associated with depression, which is consistent with findings from a national household survey administered across South African adults between 2002-04 (Tomlinson et al., 2009).

Of the studies in this review, the only one to use caregiver depression as a variable found no association with depression in HIV-infected participants (Bhana et al. 2016). In contrast, other Southern African studies have found that general emotional difficulties in HIV-infected youth are associated with caregiver depression (Lentoor, Asante, Govender, & Petersen, 2016; Louw, Ipser, Phillips, & Hoare, 2016), although Louw et al. (2016) found this to be a weaker association in HIV-infected, compared with HIV-uninfected, participants.

There is some preliminary evidence that certain household characteristics, such as water source, may have an association with depression, but the number of eligible participants from Målqvist et al.'s (2016) dataset was very low, reducing the reliability of the results. A surprising finding was that looking after a sick person in the home was related to lower levels of depressive symptoms (Woollett et al. 2017). It is possible that looking after a sick person can provide youths with a sense of purpose, which may be protective against depression. However, looking after younger children in the family was not found to be associated with depression. As a stand-alone finding in a single paper, this warrants further investigation.

Social and Community Support

This review found some evidence that both knowing one's HIV-status and disclosing it to others can be protective against depression in HIV-infected youth. This is important given that prevalence of disclosure to HIV-infected children in resource-poor settings is low (Vreeman, Gramelspacher, Gisore, Scanlon, & Nyandiko, 2013). Research on disclosure has largely focused on its association with ART adherence, with limited research on its psychological impact (Vreeman et al., 2013). Studies that have assessed psychological impact of disclosure have produced mixed findings. Self-reported emotional difficulties were found to be lower in HIV-infected Zambian youth who know their status compared with those who do not (Menon, Glazebrook, Campain, & Ngoma, 2007), while caregiver-ratings in Kenya indicated significantly higher depressive symptoms in HIV-infected youth who knew their status (Vreeman et al., 2014). This review assessed the impact of knowing one's status in samples where a high proportion of participants were aware of their status: 81% (Kim et al, 2015); and 88% (Woollett et al, 2017). This may be a consequence of the fact that participants were

recruited directly through ART clinics and, therefore, these samples may not be representative of the wider HIV-infected youth population.

Wider research on the association between depression and disclosure to others is also mixed. A study of HIV-infected youth in Namibia found disclosure to others to be associated with more mental health difficulties, although there was no direct association with emotional symptoms (Gentz, Calonge Romano, Martínez–Arias, & Ruiz–Casares, 2017). Qualitative studies have found that youth in South Africa who disclosed to teachers generally experienced increased academic support, but disclosure revealed via gossip could result in discrimination and stigma (e.g., Petersen et al., 2010). Lam et al.'s (2007) study of American 16–25 year olds found disclosure to acquaintances was associated with increased distress, while disclosure to close family friends was not, indicating that perhaps measures of disclosure need to be more nuanced than those employed in this review.

The fact that higher caregiver supervision and likelihood of seeking social support were identified as protective factors against depression is consistent with wider literature about the positive impacts of social support for HIV-infected youth (Abramowitz et al., 2009; Breuer et al., 2011; Gentz et al., 2017; Lam et al., 2007).

Past Trauma/Stressors

This review highlighted mixed findings regarding the impact of violence on depressive symptoms. Although Woollett et al. (2017) found an association between depression and several violence variables, witnessing somebody being stabbed or shot was not found to be associated with depression. In line with this, Skeen et al. (2016) recruited both HIV-infected and uninfected participants and found interpersonal violence in the home to be associated with higher depression scores, while community violence was not; this remained the case when controlling for HIV status. Community violence was related to trauma symptoms in youth (Skeen et al. 2016) suggesting that, while this does have a psychological impact on youth in Southern Africa, it does not appear to manifest as depression.

In line with Woollett et al.'s (2017) findings described in this review, Gentz et al. (2017) found no association between orphanhood status and mental health problems. Sherr et al. (2014) recruited both HIV-infected and uninfected participants and found “a trend” towards elevated depression in double orphans, although this was non-significant.

Psychosocial Factors

The association between internalised stigma and depression found in this review is consistent with research on HIV-infected adults in sub-Saharan Africa (Breuer et al., 2011; Pantelic, Shenderovich, Cluver, & Boyes, 2015), and emotional difficulties in HIV-infected youth in Namibia (Gentz et al., 2017). This has implications for intervention; indeed, a study on HIV-infected adults in South Africa found that a stigma-reducing intervention significantly reduced depressive symptoms (Chidrawi, Greeff, Temane, & Ellis, 2015). The fact that lower self-concept, social withdrawal and resignation were linked to depression offer potential targets for psychosocial interventions.

Factors Not Assessed

ART adherence was not assessed in this review, despite a well-established association between ART adherence and depression in HIV-infected youth outside of Southern Africa (Agwu & Fairlie, 2013; Murphy et al., 2001; Naar-King et al., 2006). There is also some evidence in wider literature for the following factors: level of disability (Olley et al., 2004); route of transmission (Tanney, Naar-King, & MacDonnel, 2012; Walsh et al., 2017) and sibling relationships (Snead, 2011). Other factors have yet to be assessed in relationship to depression, but may be pertinent. For example, a recent study identified significant cognitive differences between HIV-infected and HIV-uninfected participants (Sherr, Hensels, Tomlinson, Skeen, & Macedo, 2018), but the association between cognitive function and depression has yet to be assessed.

Interventions

Only two intervention studies were identified, consisting of a family programme and a school-based art intervention. Only the family programme recruited HIV-infected youth exclusively. Neither interventions led to a significant reduction in depression. Literature on interventions for HIV-infected youth outside of Southern Africa is also sparse. A global review of interventions for depression in HIV-infected individuals (Sherr et al., 2011) only identified one study of adolescents, which was USA-based and used massage as the intervention (Diego et al., 2001). Although the review found psychological interventions to be particularly effective in reducing depression, the populations studied make the findings unlikely to be generalisable to Southern African youth. In addition, interventions to be implemented in Southern Africa need to take account of the resource-poor context. A recent review identified 18 community and

school-based intervention studies that assessed depression as an outcome in youth across low and middle-income countries (Yatham, Sivathasan, Yoon, da Silva, & Ravindran, 2017). Of these, seven demonstrated a significant reduction in depression. These interventions, though not tailored to HIV-infected youth, are evidence for the feasibility of community-based interventions in resource-poor settings and indicate that they can be effective in reducing depression. In South Africa, there is evidence that community-based organisations (CBOs) are accessible to vulnerable youth and attendance is associated with reduced depression (Yakubovich et al., 2016). CBOs may therefore be a potential target for future interventions.

Strengths and Limitations

A strength of this review is the use of a clear, systematic search across four databases. Study screening, study selection and quality assessment were conducted by two independent researchers to reduce bias.

There are several limitations of this review. The dearth of research in the field means results cannot be confidently generalised and robust conclusions cannot be drawn. Measures of depression used in this review mainly relied on the adaptation of Western-developed measures, using Western conceptualisations of depression, with alternative terminology either agreed by researchers or developed from a small sample of participants (Kim et al., 2014; Snider & Dawes, 2006). The construct validity of these measures can therefore be questioned. In addition, data on risk factors were derived exclusively from cross-sectional studies, which presents the problem of determining causality between depression and associated variables. The lack of control groups in the risk factor studies, and the lack of mental health research in Southern Africa more generally, means it is unclear which risk factors are specific to HIV-infected youth and which are relevant to youth generally.

Clinical Implications

The shortage of research on depression in HIV-infected youth limits the clinical implications that can be drawn from this review. Based on the findings, neither art programmes, nor family-based CHAMP-model interventions can be recommended for reducing depression in HIV-infected youth. Results of factors associated with depression provide some preliminary evidence for potential targets for intervention. For example, family-based interventions may benefit from working to increase caregiver

supervision and supporting caregivers to inform youths of their HIV status. Schools offer a viable method of delivering large-scale, low-cost interventions. School-based interventions may benefit from focusing on reducing internalised stigma and reducing bullying of those taking medication, as well as supporting safe disclosure of HIV status to others. While having a safe community space was identified as a protective factor, not all youths had access to one. This provides support for CBOs and offers another potential target for delivering large-scale, low-cost interventions.

Future Research

While much of the psychosocial research on youth in Southern Africa refers to the high HIV prevalence of the area, or focuses on those affected by HIV (i.e. caring for a HIV-infected family member or orphaned by HIV/AIDS), most of these studies failed to record the HIV status of youth themselves, despite them being at higher risk of infection. HIV leads to biological and neurochemical changes and can have specific psychological and social consequences. Results from this review have indicated several HIV-specific variables that appear to be associated with depression, including immunosuppression, internalised stigma and being bullied for taking medication. It is therefore not sufficient to generalise findings from HIV-uninfected youth; future research should record HIV status of youth to improve our understanding of risk factors relevant to this population so that interventions can be tailored appropriately.

Further research is needed to find effective interventions for depression that are possible to deliver in the resource-limited setting of Southern Africa. To optimise viability, interventions would likely need to be community or school based, and may involve training of teachers or other community workers to deliver interventions.

Conclusions

Despite the high prevalence of HIV in youth in Southern Africa, this review has identified a distinct lack of research on HIV and depression in youth in these countries. Some preliminary evidence for potential risk factors is presented, which offer possibilities for the focus of interventions, but substantially more research is needed. Future research should consider measuring HIV status as standard and conducting separate or comparative analysis for this participant group. Research on interventions is severely lacking, but wider literature can offer some suggestions for community-based interventions that take account of the impoverished setting.

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Service Improvement Project

An evaluation of group supervision for nurses working in cancer care

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Abstract

National guidelines outline that clinical staff working in cancer services should be provided with clinical supervision. In Great Western Hospital Trust, clinical psychologists run supervision groups for clinical nurse specialists working in cancer and palliative care using the Structured Approach to Collaborative Supervision (SACS) model. This project aimed to evaluate the implementation of this supervision model based on literature about the functions of supervision and mechanisms of change within those functions. A mixed methods design was used. Results indicated that, generally, supervisees felt the normative, formative and restorative functions of supervision were being well met by the SACS model. Guidance, reinforcement, structure, and learning through others were all identified as mediators for achieving supervision outcomes within these functions. Based on the results, several recommendations were made to the service to offer potential improvements to the SACS supervision groups.

Keywords: clinical supervision; supervision model; oncology

Introduction

NICE (2004) guidelines for cancer services recommend a four-tier model of psychological assessment and support. The model outlines that all health and social care professionals working within cancer services should provide patients with compassionate communication and general psychological support. Subsequent tiers represent additional training and expertise, enabling higher levels of psychological assessment and support (see Figure 1). The guidelines state “those working at the higher levels of the model should normally provide training, supervision and opportunities for continuing professional development for those operating at the lower levels” (p.82). Clinical psychologists within cancer services are therefore well-positioned to provide supervision for tier one and two clinicians (London Cancer Alliance, 2015; National Cancer Action Team, 2010)

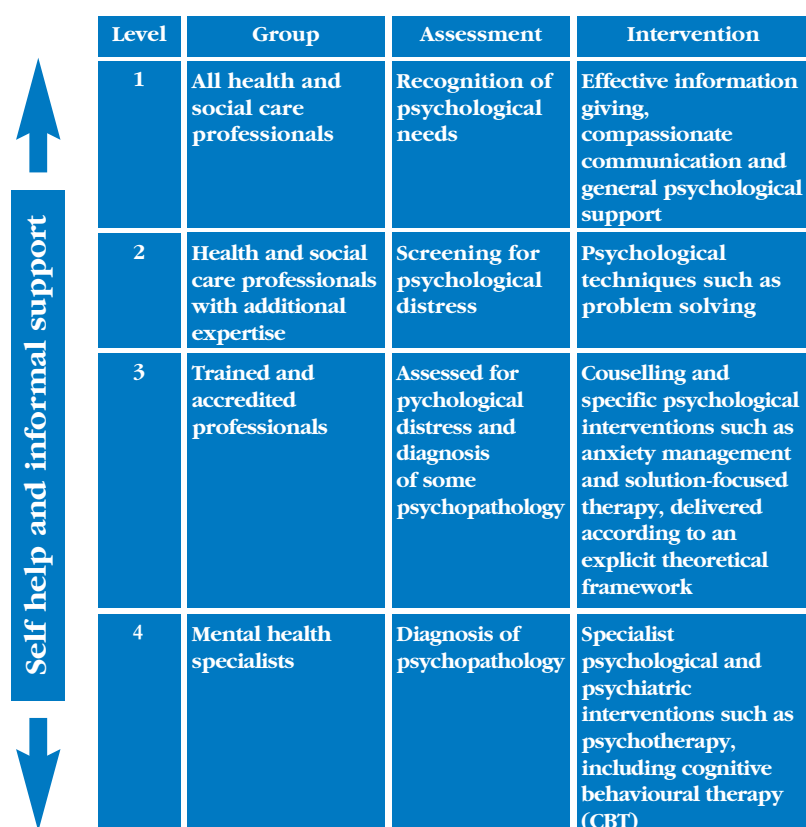


Figure 1. Recommended four-tier model of psychological assessment and support (NICE, 2004)

Definitions of clinical supervision vary across settings. The Department of Health defines clinical supervision as: “a formal process of professional support and learning which enables individual practitioners to develop knowledge and competence, assume responsibility for their own practice and enhance consumer protection and

safety of care in complex clinical situations” (DoH, 1993). Bridget Proctor’s model (Proctor, 2001) outlines three functions of supervision: formative (skill and knowledge development); normative (professional accountability); and restorative (support). A review of clinical supervision definitions found they most often emphasised promoting professional development and ensuring patient safety (Kilminster & Jolly, 2000); thus, prioritising the formative and normative aspects of supervision. However, a review of clinical supervision in nursing found restorative aspects of supervision (e.g. burnout; tedium; relationship with other nurses) were most researched and nurses tended to focus on restorative aspects during unstructured interviews (Brunero & Stein-Parbury, 2008). Clinicians in cancer services are continually working with serious illness, death and bereavement; in this context, restorative aspects of supervision are therefore important in maintaining clinician wellbeing, avoiding burnout and sustaining the delivery of high quality care (Pereira, Fonseca, & Carvalho, 2011; Sinclair & Hamill, 2007). As such, guidelines for supervision in cancer services often make explicit reference to exploring the impact of the work on the self (Criddle, 2015; Pan Birmingham Cancer Network, 2010).

Supervision models have generally attracted criticism for often having little or no empirical basis (Kilminster & Jolly, 2000). Evidence-based literature reviews have attempted to improve our empirical understanding of supervision; Brunero and Stein-Parbury (2008) identified 22 studies that evaluated clinical supervision in nursing and categorised supervision outcomes by function according to Proctor’s model (see Figure 2). Another systematic review (Milne, Aylott, Fitzpatrick, & Ellis, 2008) identified 24 supervision studies with rigorous designs and categorised outcomes according to their mechanism of change using Kolb’s (1984) experiential learning cycle. Kolb’s learning cycle is the most widely used learning theory and involves four elements, which can be broadly understood as: (a) experiencing; (b) reflecting; (c) conceptualising; and (d) experimenting. These empirical approaches are compatible; whilst Proctor’s model categorises the functions of supervision, Kolb’s model may help us to understand the mechanisms of change *within* each function.

Within cancer services, a common practice is for clinical psychologists to run supervision groups for nurses (Criddle, 2015; London Cancer Alliance, 2015). Several models of group supervision have been described in supervision literature (e.g. Arvidsson, Löfgren & Fridlund, 2001; Edmunds, 2013; Lassiter, Napolitano, Culbreth & Ng, 2008). Most share the format of one supervisee at a time presenting a question or case, before other supervisees respond. However, the focus and method of

implementation varies significantly according to the model. For example, supervisees may be asked to prepare a case, bring materials, or to speak spontaneously about a piece of work. Other group members may be encouraged to reflect on their own emotions or offer direct advice. Qualitative studies have identified that attendees of group supervision report benefiting from hearing multiple perspectives; learning vicariously through others (Carter, Enyedy, Goodyear, Arcinue, & Puri, 2009); and improved cohesion with teams (Jones, 2003), but benefits and supervision outcomes are likely to vary according to the supervision model used.

Normative: Professional accountability		
Change of action	Professional identity	Risk taking
Moral sensitivity	Confirming uniqueness of role	Job satisfaction
Problem solving	Change organisation of nursing care	Professional solidarity
Commitment affirmation	Improve individual's nursing care	Confirmation of nursing interventions
Confirmation of actions and role	Critiquing practice	Nurse patient cooperation
Identify solutions	Improving practice	Less patient resistance
Improve nursing practice		Improve patient relationship
Increase understanding of professional issues		
Formative: Skill and knowledge development		
New learning	Competence and creativity	Improved idea time
Improved knowledge	Professional development	Idea support
Professional development (deeper knowledge)	Confirming patient uniqueness	Creativity and innovation
Self confidence	Gaining knowledge	Communication skills
Self-awareness of thoughts and feelings	Competence	
Improved knowledge of human rights	Trust in self	
Recognizing family needs more	Knowledge	
	Insight into therapeutic use of self when relating to patients	
Restorative: Colleague/social support		
Listening and being supportive	Lower perceived anxiety	Improved relationship with nurses
Improved coping at work	Understanding colleagues	Trust
Accessing support	Increased interest	Reduced conflict
Better relationship amongst staff	Relief (discuss thoughts and feelings)	Reduced tedium
Engagement in the workplace	Relief of thoughts and feelings	Reduced burnout
Safe group environment	Empathy	Personal accomplishment
Sense of security	Sense of community	Personal development
Satisfaction with nurses	Catharsis	Coping
	Self understanding	

Figure 2. Reported outcomes of supervision, categorised according to Proctor's model (Brunero & Stein-Parbury, 2008)

In line with good practice (National Cancer Action Team, 2010; NICE, 2004), Great Western Hospital NHS Foundation Trust (GWH) provide group supervision to cancer nurses. Groups are run monthly or six-weekly by clinical psychologists using the Structured Approach to Collaborative Supervision (SACS) model. SACS (see Appendix C) was created by Linda Charles, a psychologist who provides national supervisor training for the BPS. SACS allocates roles to those attending the group: facilitator; case presenter; co-supervisors; and scribe. Within GWH, clinical psychologists take the

facilitator role. Each session, two nurses take turns as case presenter. The case presenter outlines a supervision question, provides a 5-7 minute description of the case, then chooses a method of feedback from six options: sounding board; advice; show me; reflecting team; brainstorming or flip the question. Co-supervisors use the chosen method to help answer the supervision question. Finally, the case presenter reflects to the group specific points they will take forward. Sessions are 60–75 minutes long.

Conceptually, SACS is congruous with both Proctor's (1991) and Kolb's (1984) models. Case presenters choose a supervision question which could link with normative, formative or restorative aspects. SACS uses co-supervisors to support reflection and case presenters are encouraged to conceptualise their learning and plan active experimentation. This active focus on the learning cycle in supervision is believed to lead to better patient outcomes (Kilminster & Jolly, 2000). Theoretically, SACS offers a replicable framework that could fulfil Proctor's functions of supervision, by facilitating Kolb's learning cycle. However, SACS has yet to be evaluated in its effectiveness. This project aims to evaluate the effectiveness of SACS for cancer nurses at GWH and develop recommendations on how to improve supervision effectiveness.

Evaluation questions

- How effective is the SACS model of group supervision at providing formative, normative and restorative functions of supervision for supervisees?
- How does SACS facilitate supervision outcomes in relation to Kolb's learning cycle?
- How can SACS be applied in such a way as to improve supervision outcomes?

Method

Design

A mixed-methods cross-sectional design was used, using questionnaire and focus group data.

Participants

Individuals were eligible to participate if they attended any of the three SACS supervision groups at GWH. Participants were cancer nurses who had undertaken level two psychological support training (NICE, 2004). See Table 1 for composition of supervision groups at time of data collection and Figure 3 for flowchart of recruitment.

Table 1. Characteristics of supervision groups; all members eligible for participation

	Facilitator	Number of members	Frequency of sessions	Duration of group at time of project
Group A	Psychologist 1	6	Monthly	Six months
Group B	Psychologist 2	6	Six-weekly	One year
Group C	Psychologist 2	5	Monthly	Two years

Evaluation Questionnaire

A questionnaire previously developed to evaluate a level two cancer supervision group (BPS, 2015), was adapted to evaluate the past six months of supervision, rather than session-by-session (see Appendix D). The questionnaire consists of 11 positive statements about supervision; participants are asked to rate level of agreement with each statement from 1–5. A twelfth item asks participants to rate their confidence in discussing psychological problems with patients with cancer, from 1–10.

Each item on the evaluation questionnaire was categorised according to the supervisory function it best measured (formative, normative or restorative).

Categorisation was done by two independent raters, with good agreement.

Discrepancies were resolved by a third rater. See Table 2 for item categorisation.

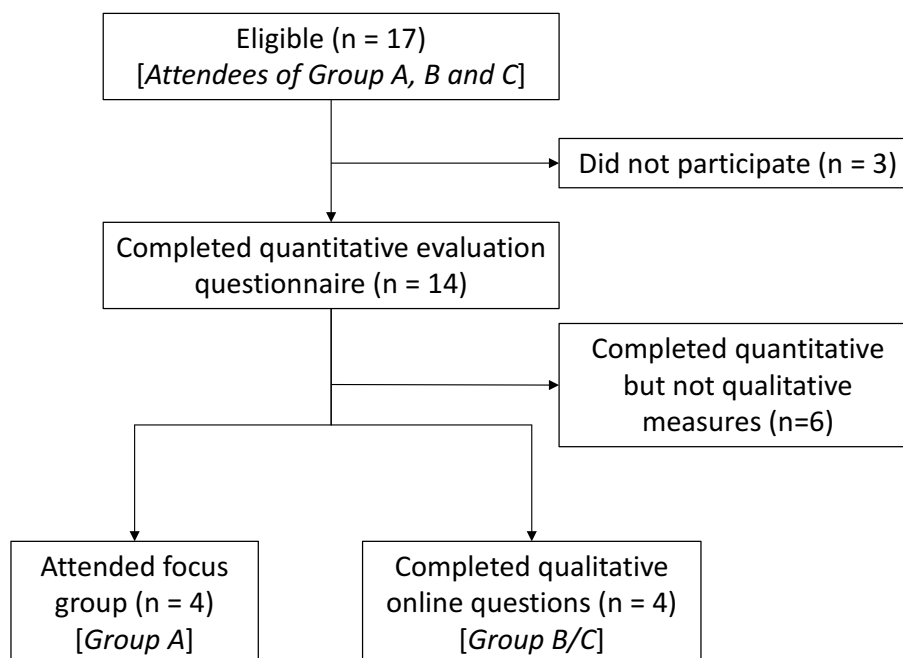


Figure 3. Flowchart of participant recruitment

Focus Group Questions

Broad focus group questions were developed to allow for more in-depth evaluation of how SACS facilitates Kolb's learning cycle to meet the three functions of supervision. More specific focus group questions were developed based on lowest-scoring items from completed evaluation questionnaires and focused on how these outcomes could be better met. Focus group questions were based on scores from the nine quantitative questionnaire respondents who returned their responses prior to the focus group (Group A=5; Group B=4). See Table 3 for focus group questions.

Table 2. Categorisation of items in evaluation questionnaire and mean scores

Questionnaire Item	Primary supervision function	Mean score from Group A (n=5)	Mean score from Groups B and C (n=9)	Overall mean (n=14)
1. I feel that this group is a safe space to reflect, ask questions, share my ideas and experiences	Restorative	4.8	3.7	4.1
2. I feel supported by other people in the group	Restorative	4.8	4.0	4.3
3. When I have shared something with the group I felt heard by them	Restorative	4.8	4.2	4.4
4. I feel that other group members treated my contribution with respect when I shared something with them	Restorative	4.8	4.2	4.4
5. I feel reassured that what I am doing as a professional to support cancer patients is good enough	Normative	4.4	3.8	4.0
6. I feel that the way cases are discussed in this group is helpful for me	Formative	4.8	3.0	3.6
7. By attending the group, I have considered how I look after myself	Restorative	4	2.7	3.1
8. I have regularly shared or addressed issues relevant to working with cancer patients	Normative	3.6	3.7	3.6
9. I have come away from the group understanding a bit more about the experience and needs of a person with cancer	Formative	5	2.9	3.6
10. As a result of attending the group I understand more about responding to patient distress	Formative	4.6	3.1	3.6
11. I have learnt something useful about how to deal with challenging situations with my patients and their families	Formative	4.8	3.3	3.9
12. Overall, how confident do you feel about discussing psychological problems with your patients with cancer? (Scored out of 10)		8.5	7.8	8.3

Note: Items 5, 6, 7 and 8 used to develop questions for focus group based on scores from questionnaires received prior to group

Procedure

Nurses were invited to complete the evaluation questionnaire at the end of one of their supervision sessions. Information sheets about the project were provided alongside paper copies of the evaluation questionnaire. Envelopes and boxes were provided and the facilitator left attendees alone to allow anonymous submission.

All 17 supervision attendees were invited, via email, to attend a focus group. Only four attended, all of whom were from Group A. It was reflected by the researchers that Groups B and C had been provided with less notice of the focus group than Group A, which may have inhibited their attendance. To allow Supervision Groups B and C a further opportunity to provide feedback, anonymous online questionnaires were emailed to attendees of these groups. This consisted of the evaluation questionnaire (which could be skipped if participants had already completed it), as well as four optional qualitative questions based on the focus group questions.

Focus group attendees and online questionnaire respondents were also asked to rate how well supervision groups adhere to SACS from 0–10.

Ethics and Governance

University of Bath ethical approval was obtained. Great Western Hospital Trust also granted approval for this evaluation (Appendix E).

Qualitative Data Analysis

Thematic analysis was carried out according to Braun and Clarke (2006), using a realist method. An inductive approach was taken to coding and the identification of themes at the semantic level. However, the researchers acknowledge that prior knowledge of relevant literature and development of the research question will have informed interpretation of themes. The primary researcher was a trainee clinical psychologist who had not previously run supervision groups and had no personal experience of SACS.

The focus group was orthographically transcribed, to include all verbal and non-verbal utterances. The transcript was then read several times and initial notes about patterns and potential codes were made. The entire transcript was then systematically coded using NVivo, with the same piece of text often categorised under multiple codes. Responses to qualitative items in the online questionnaire ($n=4$) were also coded. Codes were then grouped into themes and sub-themes using a thematic map format. Different iterations of mind-maps were saved in order to preserve the audit trail (Nowell, Norris,

White, & Moules, 2017). During the refinement phase (Braun & Clarke, 2006) quotes were checked against themes and changes were made so that themes appeared in a coherent pattern (Nowell et al., 2017). To improve robustness, peer debriefing with an independent researcher was used to support the defining and naming of themes (Nowell et al., 2017). This led to further refinements to theme structures and names; all changes were recorded.

Table 3. Main questions asked in semi-structured focus group

<ul style="list-style-type: none"> • What is your understanding of supervision in Cancer Nursing care? • What do you find <i>most</i> useful about attending supervision groups? • How could the supervision groups be improved? • How could supervision ensure that everybody in the group is able to regularly share, or address issues relevant to cancer patients? • How could the supervision groups improve how you look after yourselves, as individuals and as teams? • How could the supervision groups help you to feel more reassured that what you are doing as a professional, to support cancer patients, is good enough? • What's helpful and unhelpful about <i>the way</i> that cases are discussed in the supervision groups?
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Results

Evaluation Questionnaires

Scores across all three supervision groups produced a mean of 3.8 out of five for normative items; 3.7 for formative items; and 3.2 for restorative items. There were differences in scores between groups, with Groups B and C demonstrating lower agreement than Group A on 11 of the 12 questionnaire items. All responses are summarised in Table 2.

Adherence to the Model

Nine participants rated adherence to SACS. Mean rating was 9 (range 8–10), indicating high adherence to SACS across supervision groups.

Summary of Thematic Analysis Findings

Four main themes were identified from the qualitative data: (1) dedicated space; (2) value of supervision; (3) mediators for supervision outcomes; and (4) challenges. Each theme contained sub-themes, as illustrated in Figure 4. Participants 1–4 are focus group attendees and participants 5–8 completed the online questionnaire.

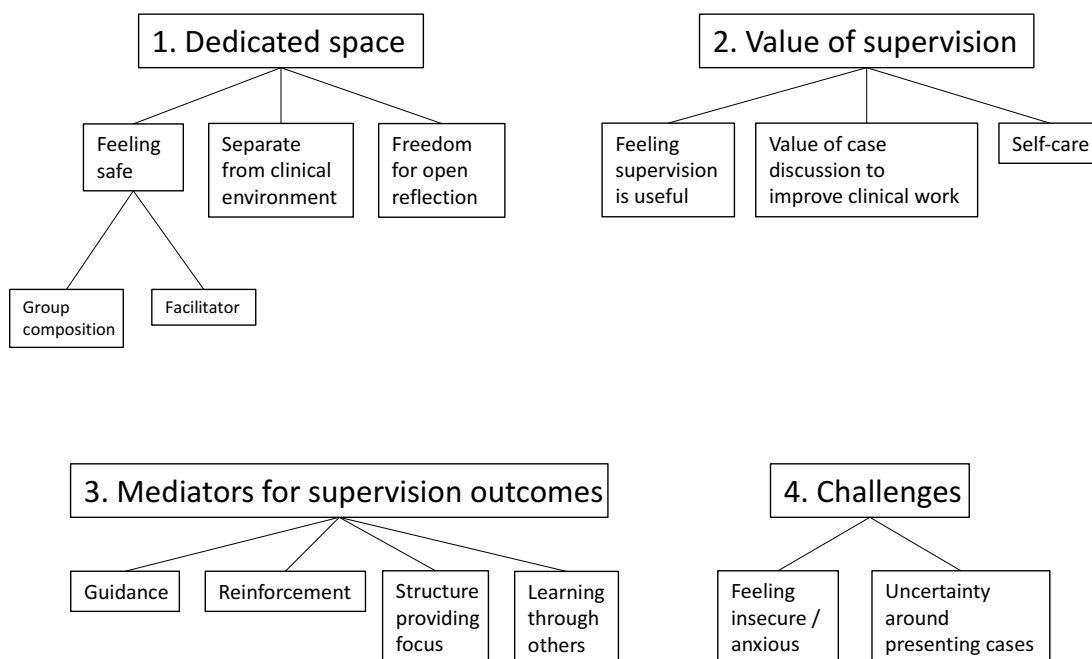


Figure 4. Thematic map illustrating four main themes with sub-themes

Dedicated Space

Supervision groups were viewed as a dedicated time and space, with characteristics and qualities that make it distinct from both clinical work and other forms of support. Within this theme were three sub-themes: (a) importance of feeling safe, which was further divided into (i) group composition and (ii) facilitator; (b) separation from clinical environment; and (c) freedom for open reflection.

Feeling safe. Participants reflected on aspects of group supervision that made them feel comfortable in discussing issues. These could be conceptualised into two smaller themes.

Group composition. The make-up of the group, both in terms of size and characteristics of other supervisees, was important to participants. Focus group participants felt it was important that there were not too many members in their supervision group and that the current group size of six felt right.

I think if it got much bigger, (a) we wouldn't have the opportunity to talk, but also, you'd feel probably less comfortable if there's like a massive group.
(Participant 2)

An online participant noted a difficulty that can occur in having smaller groups.

Groups are small—people don't always have examples to share or things to say
(Participant 7)

It was recognised that interpersonal relationships between supervisees is an important aspect in allowing them to feel safe to discuss certain issues.

The people who you're with, you know, it has to work, doesn't it really? And not everybody will necessarily gel with everyone, so I think that, that would have an impact, but I think, it works quite well (Participant 4)

Working relationships with other supervisees were also considered; participants reflected that being supervised with others outside of their immediate team made it easier to discuss any issues relating to colleagues. Issues of power difference between group members was also touched upon.

You might have something that you wanna discuss that's quite sensitive. Wouldn't necessarily feel that you could do that...if you were in with your line manager.
(Participant 2)

Characteristics of the facilitator. Participants reflected that they felt safe being led by the facilitator, which was important for feeling comfortable participating in discussions.

You don't feel daft about saying things. Well you might still feel daft, but she doesn't make you feel, you know, um, just accepts it as it is (Participant 4)

For some this differed to previous experiences and so participants identified the characteristics of the facilitator that allow them to feel safe.

Participant 1: She's friendly, she listens. Not judgemental.

Participant 3: She's very calming as well.

Participant 4: Reassuring, isn't she?

Separate from clinical environment. Participants spoke about supervision groups offering a protected, dedicated time that allowed space to reflect, that would not otherwise be available to them.

Work is very busy and it gives staff the time to look and reflect on challenging situations (Participant 6)

*Otherwise the opportunity's not there, apart from in these sessions
(Participant 2)*

The physical separation from the everyday clinical environment seemed to be important in facilitating an appropriate atmosphere.

But when you're in a clinic room, next to consultant clinics that are running, in your normal clinical area...shoving chairs all in...like literally teeny, and you're all clumped together, it just doesn't feel right, for that sort of session. Whereas now...we're in a separate room. It's a bit more comfortable. (Participant 2)

Freedom for open reflection. Participants emphasised that these supervision groups allowed them to discuss issues other than patients and relatives—for example, work relationships or relevant personal issues. Participants therefore felt that supervision gave them permission and freedom to talk about things that otherwise did not get addressed.

Yeah. And it's not just patients or relatives. We're allowed to talk about colleagues, or, peers, or whoever (Participant 2)

What's nice about this is we can talk about things outside of work, so if things from our personal life are impacting, whereas before we were told we couldn't, but now, we can (Participant 3)

[There] is a link between home and work and sometimes they cannot be separated and do have an impact with how with [sic] manage situations at work (Participant 5)

Value of Supervision

This theme related to the value that participants saw in attending supervision groups and meaning it had to them. It was further divided into three sub-themes: (a) feeling supervision is useful; (b) value of case discussion to improve clinical work; and (c) self-care.

Feeling supervision is useful. Participants reflected the importance of feeling that they gained something from attending supervision and this impacted their motivation to attend. Some participants reflected on past experiences where the gains had been less clear to them.

I just pulled out, because I didn't get anything out of it (Participant 4)

So before, when we started supervision we had nothing to compare it to and we thought "oh, well if this is it...do we really need to come?" (Participant 3)

Comparisons were drawn with the current groups where participants feel supervision is more useful.

It felt like it was a bit more, to do with what somebody else needed to tick off, rather than what you were actually getting out of it. But now, you know, I certainly feel like I get something back (Participant 2)

There's no more time in the day, but you feel like you're getting something back, so therefore there's more meaning to it, so therefore it is something I want to do. Whereas before, it was just like "oh, it's that time of the month again, [inaudible] I really can't do this" (Participant 2)

Myself and my colleagues have appreciated this service (Participant 6)

Value of case discussion to improve clinical work. A supervision outcome that related to the value of supervision was the benefits for future clinical work.

So then future appointments or conversations or if we're meeting with that, that person, you know, if, if they're acting or, or coming across in the same way, it helps you deal with it, better (Participant 4)

So you can then look at it from a different angle and think "actually yeah, I could've done that" or "I did do that, but this happened" or, and sort of, take it from that experience (Participant 1)

Self-care. Participants reflected on benefits of supervision that related to caring for themselves and this contributed to the value of supervision.

It's also self protection isn't it? Looking after yourself and...talking about things that you may not have, normally have time to talk about (Participant 3)

Well from the nature of the..., you know, the fact that they've got cancer, we often find...patients can present with feelings of anger or...sadness, or loss, and sometimes it's directed at us, but it might not be directed at us, if you see what I mean. So it's dealing with, how that makes you feel, as well as how you deal with the situation when it's happening. 'Cause it can feel personal sometimes. (Participant 2)

To ensure that our 'well being' is being addressed and managed. (Participant 5)

However, participants recognised there may be further opportunity to do this.

Talking about strategies of how to, look after ourselves, so, like a session on that would be good (Participant 1)

Mediators for Supervision Outcomes

This theme captures *how* participants believe supervision facilitates the outcomes of caring for self and improved clinical work identified in the previous theme. There are four sub-themes: (a) guidance; (b) reinforcement; (c) structure providing focus; and (d) learning through others.

Guidance. Participants noted that the facilitator has a role in guiding supervisees. This was linked to having a different professional background and approaching things from a different angle.

You'll kind of say, "well this is what I'd like to talk about, but I'm not quite sure how to structure it" and she'll kind of, say, "what about this?"...She'll guide you as well (Participant 2)

Reinforcement. Participants spoke about feeling reassured that what they were doing was acceptable and feeling validated by others doing similar roles.

I think it validates what you do, doesn't it, so if you, if you bring a case and discuss it, "oh yeah, I would have done that", like it just gives you validation that you're doing things ok (Participant 3)

Structure providing focus. Throughout the focus group data, participants spoke about the helpfulness of having the SACS structure. Participants noted that they know what format to expect and this allows them to prepare for supervision. Again, this contrasted with some participants' past experiences of supervision.

I think before, we used to just, we used to just turn up, I'd struggle to think about something to talk about, but now I know how it's going to be structured then I can relate it to a certain scenario, to how it's going to work in the session, if that makes sense (Participant 2)

Because there's a question at the beginning you've got to think about what your scenario is and then you get the opportunity to talk (Participant 2)

Before it just seemed to be an offloading session (Participant 3)

Learning through others. Participants spoke about the usefulness of hearing others' perspectives and using this as a way of generating new ideas.

And then hopefully get some feedback on, from others, that we know, do similar roles to, to us as to how that went and how we could maybe do things better in the future (Participant 1)

I think that if we'd have had individual supervision at the moment, I think you'd learn from it, but I think you learn more as a group. (Participant 1)

Participants clearly valued hearing ideas from others. This was demonstrated when participants spoke about how they choose how to receive feedback from others during supervision groups.

Participant 2: And being able to choose how you have your feedback.

Moderator: And how does that work in practice?

Participant 2: We always go for the same one [laughs]

Moderator: do you?

[laughter]

Participant 4: I was gonna say...we're creatures of habit!...I think someone, I think <name> chose the reflecting team, dun't she?

Participant 1: Mmm

Participant 2: But generally...I think it is the brainstorming one

Participant 3: We don't do the roleplaying one

Some participants spoke about learning through others by simply observing and allowing more experienced supervisees to model.

It's just a learning curve for me to just absorb how, you know, the rest of my colleagues deal with things, before I speak up about anything (Participant 1)

Challenges

Although focus group participants were very positive about their experiences of supervision, the dataset also captured some challenges related to attending the SACS supervision groups, which were divided into two subthemes: (a) uncertainty around presenting cases; and (b) feeling insecure/anxious.

Uncertainty around presenting cases. Some participants expressed uncertainty around what constituted a 'good case' to discuss in the groups. One participant spoke

about thoughts that the case presented at supervision had to have specific characteristics.

Participant 4: I'd have to cause a row somewhere [laughs], no, but...I wouldn't like that...'cause then the pressure's on

Moderator: ...what would the pressure involve?

Participant 4: Coming up with a scenario that you can talk about

Moderator: Ok. Does it feel like the scenario's got to be a certain way?

Participant 4: Be a goodun [laughs] well to be juicy enough to talk, that's how I, yeah, that's, I suppose how I perceive it

There was also some doubtfulness about the usefulness of discussing cases if they are not current.

'Cause I am somebody who just kind of deals with things, and moves on, I, so I do struggle coming up with a scenario (Participant 4)

'Cause that's what I struggled with initially, was getting my head round the fact that, if something's happened I wanna talk about it straight away, I don't wanna wait for a month...So, once I got my head round that then I was able to bring things to the group...Because it might be that you've already dealt with it, but you wanna know how to deal with it better, or next time (Participant 2)

Feeling insecure/anxious. Some participants spoke about feelings of insecurity and anxiety in relation to group supervision. An aspect of this related to worries about how participants might be perceived by others, which seemed to partly relate to having less professional experience.

And I think that's because I've not been doing this before, so I'm kind of thinking, "what are the topics that we are going to talk about? How are people's reactions in the group gonna be?" (Participant 1)

I suppose maybe that you just feel you can participate more, whereas before I was very much like you because I was with experienced CNS's and thinking

“they ain’t gonna wanna listen to what I gotta say” because, you know, they’ve, they had more experience and more things to say (Participant 4)

An online participant found the sessions’ structure and the generation of supervision questions stressful and anxiety-provoking.

I personally feel that a less structured approach without set tasks would suit me better. A structured approach makes me feel quite anxious about the session...I sometimes find it more stressful trying to think of a 'question' than actually presenting a case (Participant 5)

Discussion

This study used a mixed methods, cross-sectional design to evaluate the effectiveness of SACS. Participants’ ratings indicated that supervision groups at GWH adhere well to SACS, suggesting participants’ accounts of supervision accurately pertain to the implementation of the SACS model.

The evaluation questionnaire was used to assess the effectiveness of SACS in fulfilling the formative, normative and restorative aspects of supervision expected from the service context. Overall ratings suggested that items relating to normative functions were best met by the supervision groups, and items relating to restorative functions were least well met. It is worth noting that there was a difference between supervision groups in their ratings on the evaluation questionnaire, with Group A rating the supervision groups as meeting the three functions better than Groups B and C. Such differences could be due to several factors including different facilitators, how long group had been established for, group dynamics and group composition (bandings, specialities, etc.).

A focus group and qualitative questionnaire were conducted to assess how SACS facilitates these supervision functions in relation to Kolb’s learning cycle and whether this could be improved. Participants recognised that supervision groups provide a space to reflect and think about cases in a way that is not otherwise available. The results suggested that feeling safe was a fundamental requirement to enable participants to engage with supervision and the associated learning. The size of the group, the characteristics of other members and the facilitator all contributed to the sense of safety. The warmth and positive regard recognised in the facilitator are hypothesised to

encourage change (Rogers, 1995). These aspects, while not specific to SACS, are nonetheless essential foundations for supervisees to engage optimally with SACS.

Similarly, participants recognised clear benefits from attending SACS groups and, as a result, valued them and felt motivated to attend. Participants described ‘getting something out of’ SACS supervision in a way that differed to previous supervision experiences. The tangibility of supervision ‘outcomes’ theoretically links with the conceptualisation and experimentation stages of Kolb’s cycle, where some past experiences of supervision may have gotten ‘stuck’ at the reflecting stage. Previous research has found that nurses tend to focus on restorative benefits of supervision (Brunero & Stein-Parbury, 2008). Correspondingly, this study identified a theme of self-care. Restorative aspects are important for maintaining staff wellbeing and reducing burnout, which influence the quality of care delivered (Pereira et al., 2011; Sinclair & Hamill, 2007). However, participants also spoke about the value of case discussion in improving clinical work, thus additionally identifying the formative function of supervision.

The ‘mediators for supervision outcomes’ theme aligned most closely with the research question on how supervision functions were facilitated. For focus group participants, the implementation of SACS coincided with a new facilitator and both aspects were important mediators for participants. Many participants felt that the structure of SACS provided focus, allowed supervisees to know what to expect and prepare. Beginning supervision with a defined question encouraged supervisees to consider the purpose of their case presentation and think about what they wanted to come away with. However, some participants found the structure—in particular, generating a supervision question—stressful or anxiety-provoking, which, in some cases led to avoidance of bringing cases to supervision. Whilst there is learning to be derived from contributing to other people’s supervision questions, this limits the capacity to reflect on one’s concrete experience, as outlined in Kolb’s learning cycle. Vygotsky’s (1987) ‘zone of proximal development’ (ZPD) theory has previously been applied to supervision and outlines that learning is optimal when supervisees are reasonably challenged outside their comfort zone, with appropriate scaffolding to enable them to achieve the task (James, Milne, Marie-Blackburn, & Armstrong, 2007). Results from this study highlight that different supervisees within the same group are likely to have different ZPDs. Therefore, while supervisees will gain most from being pushed outside their comfort zone, those who find it challenging to produce a supervision question may need scaffolding to master this task. Further guidance on the SACS model (L. Charles,

personal communication, September 5, 2017) includes additional options for methods of feedback, such as “What is THE Q?” where co-supervisors support the case presenter towards clarity about the work to be done by suggesting questions they might choose facing this situation. This could provide a useful option for supervisees who need more practise in considering their supervision question.

In line with previous research on group supervision (e.g. Carter et al., 2009), participants highlighted vicariously learning through others and hearing multiple perspectives as an important mediator for supervision outcomes. This was valued by participants, as evident from participants’ choice of feedback from SACS. This appeared to promote the reflecting and conceptualising parts of Kolb’s learning cycle. However, Gordon (2012) argues it is important to be aware of supervisees’ blind spots and take note of what is not brought to supervision. Therefore, supervisees who consistently choose the same method of feedback may benefit from being encouraged to try other feedback options; again, this could encourage supervisees into their ZPD. In addition, more active feedback methods, such as ‘show me’, could promote the experimentation and experiencing parts of the learning cycle.

In relation to restorative functions, reinforcement/validation seemed to be an important mediator. The fact that focus group attendees had similar roles to one another seemed to be important for providing a sense of shared experience and validation.

Limitations

Although there was a good response rate for the evaluation questionnaire (14 of possible 17), no members of supervision Groups B or C attended the focus group, making it difficult to ascertain the cause of the difference between groups in questionnaire ratings. An important limitation of the qualitative data is therefore that it is biased towards the group that viewed supervision more favourably and may not represent the views of the views of other attendees. Attempts were made to overcome this by inviting nurses to complete qualitative questionnaires, but responses to the qualitative questions were brief. Nevertheless, the results provide detailed data about how focus group attendees felt supervision fulfilled Proctor’s functions.

As is the case with much of the supervision literature, this evaluation was based solely on reports from supervisees, with no objective measure of supervision outcomes.

Finally, this study represents an evaluation of one group supervision model, with no comparison to other models.

Implications and Recommendations

Despite the limitations of the current study (namely, the potential bias in the sample and lack of comparison with other models), findings indicate that overall, participants felt the implementation of the SACS model was effective at facilitating supervision outcomes. Based on the data available in this study, several recommendations were made to the service. Recommendations included to continue with facilitated implementation of the SACS model, but to make adaptations to ease the stress and anxiety felt by some attendees in relation to generating supervision questions. This may include collaborative development of 'group rules', implementation of an additional method of feedback to support attendees with generating questions, and development of a leaflet for supervisees to explain the rationale behind challenging supervisees into their ZPD. See Table 4 for full recommendations.

Conclusions

Results from this project suggest that many participants found SACS to be effective at providing formative, normative and restorative functions of supervision, although conclusions are limited by the potential bias in the sample. The structure of SACS encourages movement through Kolb's learning cycle within these functions. Other factors were also identified as important for effectiveness of the groups. Several recommendations have been made to offer potential improvements to the implementation of SACS in group supervision.

Table 4. Recommendations to the service based on outcomes from the study

1. Continue to allow supervision questions related to restorative functions	Participants emphasised the importance of acknowledging the impact on self and to recognise the influence of work and home life on one another. Restorative aspects are supported in literature on staff wellbeing and burnout.
2. Continue facilitated use of the SACS model	Participants felt the warm, non-judgmental stance of the facilitator helped create a safe space and the facilitator's professional background and guidance helped their learning.
3. Introduce 'what is THE Q' as a feedback option	Some participants found it difficult and stressful to generate supervision questions and this posed a barrier to their full participation and learning. Facilitating support with generating a question may provide appropriate scaffolding to enable these supervisees to bring cases more often.
4. Negotiate with supervisees a non-threatening way of encouraging all supervisees to bring supervision questions	Bringing a case/question to supervision allows reflection on concrete experience, which is part of Kolb's learning cycle. For equity of learning, it is therefore important that everybody has opportunity to bring cases. However, some participants felt that allocating specific slots to individual supervisees would be too anxiety-provoking. Other ways of distributing supervision questions could be discussed and negotiated as part of the group rules.
5. Consider use of supervision contract	Co-creation of a contract to capture shared group 'rules', goals and expectations would make sure that the agenda is transparent (e.g. how often supervisees are expected to bring cases). This could be regularly reviewed to allow amendments.
6. Facilitators to take active role in encouraging use of different feedback methods	To address supervisees 'blind spots' and bring them into their ZPD, supervisees may need encouragement to try different methods of receiving supervision feedback if they consistently choose the same method.
7. Development of an information leaflet for supervisees	A leaflet for supervisees could contain the follow things: <ul style="list-style-type: none"> • The purpose of case reflection (to address the fact that some participants were unsure about the utility of reflecting on past cases/what constitutes 'a good case') • Examples of supervision questions (to support those who find it difficult to generate questions) • Reasons that supervisees may be invited to bring their own questions, or try out a different feedback method • Encouragement to speak to the facilitator if any difficulties/anxieties arise • Recommendation to keep 'supervision notes journal' to support development of questions prior to session
8. Use of feedback forms	Session by session feedback would allow ongoing evaluation. This could also measure the impact of the implementation of any changes.
9. Consider the boundaries of restorative support and make staff aware of additional support options	Whilst attending to self-care in supervision is important for supervisees, staff should be made aware of additional forms of support for occasions when the need for personal support is beyond the remit of supervision groups
10. Further evaluation of group composition for all groups	Focus group attendees reported characteristics of their supervision group helped them to feel safe. This included size (around six members), members from different teams, and no hierarchical roles between members. However, the composition of the other groups has yet to be evaluated.

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Main Research Project

Illness perceptions in adolescents with chronic fatigue syndrome and other physical health conditions: Application of the common sense model

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Abstract

Background: Chronic fatigue syndrome (CFS) in adolescents is associated with severe functional impairment. CFS is distinct from other physical health conditions in that individuals can experience high levels of uncertainty, stigma and disbelief from others. Illness perceptions in CFS are therefore of particular interest and have implications for treatment. However, research on illness perceptions in adolescents is limited. This study compared illness perceptions in adolescents with CFS with other physical health conditions.

Method: Adolescents (aged 11–18) with CFS ($n = 49$), type 1 diabetes ($n = 52$) and juvenile idiopathic arthritis ($n = 42$) were recruited through NHS clinics and online and completed a series of questionnaires.

Results: Adolescents with CFS differed on the perceived consequences, timeline, personal control, treatment control, identity and understanding dimensions of illness perceptions. Except identity, these dimensions were predicted by health condition even when accounting for age, gender, fatigue, physical functioning, anxiety and depression.

Conclusions: Results offer preliminary evidence for the applicability of the CSM in adolescents, with implications for supporting adolescents with physical health conditions. Results suggest that psychological interventions targeting perceived control, understanding and identity may have particular utility for adolescents with CFS.

Keywords: CFS; JIA; diabetes; illness representations; common sense model

Introduction

Chronic Fatigue Syndrome (CFS), or Myalgic Encephalomyelitis (ME), is characterised by prolonged, debilitating and unexplained fatigue, alongside other symptoms that can include cognitive, sleep and musculoskeletal problems (Fukuda et al., 1994; NICE, 2007). The estimated prevalence of CFS in children and adolescents varies according to the diagnostic criteria used, ranging from 0.11–2.34% (Farmer, Fowler, Scourfield, & Thapar, 2004). The aetiology of CFS is not fully understood, but genetics, viral infection, immune and endocrine factors, stress, illness perceptions, psychiatric mechanisms and activity levels potentially contribute to its onset and/or maintenance in adolescents (Lievesley, Rimes, & Chalder, 2014). Several biopsychosocial theoretical models of CFS have been proposed to conceptualise how these factors may interact and form predisposing, precipitating and perpetuating factors in the development of CFS (e.g. Harvey & Wessely, 2007).

The functional impairment associated with CFS in adolescents is considerable. CFS has been identified as the biggest cause of long-term sickness from school (Crawley, Emond, & Sterne, 2011; Dowsett & Colby, 1997), with one study reporting an average of one year absence from school in adolescents with CFS (Rangel, Garralda, Levin, & Roberts, 2000). Adolescents with CFS also report functional impairment for carrying out activities at home (Garralda & Rangel, 2004) and impaired social functioning (Rangel et al., 2000). The impact to the individual is therefore substantial.

As there is no definitive, objective test of its presence, CFS can only be diagnosed after exhaustive physical investigations and psychiatric assessment to rule out other potential causes of fatigue such as anaemia, hypothyroidism and primary depression (Afari & Buchwald, 2003; Devanur & Kerr, 2006). This can lead to certain psychosocial challenges specific to the illness experience in CFS. Qualitative analysis of interviews with adolescents with CFS identified a number of themes around uncertainty about: the future, the validity of CFS (experiencing disbelief and distrust from family, friends and teachers) and about how to explain it to others (Fisher & Crawley, 2012). Several other studies have acknowledged the stigma associated with CFS, including a general ‘lack of permission’ from society to be ill in the absence of recognised disease. (Nettleton, 2006). Trainee medics have been found to express negative attitudes towards individuals with CFS (Stenhoff, Sadreddini, Peters, & Wearden, 2015) and over a third of adult CFS patients report that a physician has failed to legitimise or acknowledge the reality of their experience (Lehman, Lehman, Hemphill, Mandel, & Cooper, 2002). Perceived stigma has been rated as higher in CFS

than in other physical health conditions, including other “medically unexplained” conditions (Looper & Kirmayer, 2004). Thus, the illness experience in CFS is subjectively different to other physical health conditions.

The Common-Sense Model of illness representation (CSM; Diefenbach & Leventhal, 1996; see Figure 1) proposes that individuals hold implicit cognitive and emotional perceptions of their illness (Hagger & Orbell, 2003). These perceptions are influenced by somatic experiences, social and cultural beliefs, and knowledge derived from others, including professionals (Petrie & Weinman, 2006). Cognitive illness perceptions are made up of: illness identity (label given and symptoms attributed to the illness by the individual), perceived cause of the illness, timeline (how long the individual believes the illness will last), beliefs about controllability or curability, and beliefs about the illness’s consequences. The illness perception questionnaire (IPQ; Weinman, Petrie, Moss-Morris, & Horne, 1996), revised illness perception questionnaire (IPQ-R; Moss-Morris et al., 2002) and brief illness perception questionnaire (BIPQ; Broadbent, Petrie, Main, & Weinman, 2006) have all been devised to measure the components of cognitive and emotional illness perceptions.

Illness perceptions are important because they guide coping responses and illness management, which in turn influences medical, psychological and behavioural outcomes (Petrie, Jago, & Devcich, 2007). Several studies have demonstrated that negative illness perceptions (e.g. beliefs about more symptoms being associated with the condition, more severe consequences, longer timeline) are associated with increased disability, slower recovery and poorer quality of life, independent of initial medical severity of the condition (Hagger & Orbell, 2003; Petrie & Weinman, 2006). This finding has been supported in adults with a wide range of physical health conditions including chronic pain (Costa, Vale, Sobral, & Graca Pereira, 2015), COPD (Zoeckler, Kenn, Kuehl, Stenzel, & Rief, 2014), congenital heart disease (Schoormans et al., 2014), chronic kidney disease (Knowles, Swan, Salzberg, Castle, & Langham, 2014), asthma (Kaptein, Klok, Moss-Morris, & Brand, 2010) diabetes (Broadbent, Donkin, & Stroh, 2011) and CFS (Heijmans, 1998; Moss-Morris, Petrie, & Weinman, 1996). In line with the CSM, there is evidence that illness perceptions in CFS are distinct in comparison to other physical health conditions; for example, greater identity and consequences perceptions, but more acute timelines have been observed in adults with CFS compared to diabetes, chronic pain (Weinman et al., 1996) and rheumatoid arthritis (Moss-Morris & Chalder, 2003), even when physical functioning is comparable (Moss-Morris & Chalder, 2003). Such findings indicate that illness perceptions may be of

particular relevance in CFS and may be related to the distinct illness experience. As illness perceptions are associated with adaptive outcomes in CFS (Heijmans, 1998; Moss-Morris et al., 1996), they could be conceptualised as a perpetuating factor within a biopsychosocial framework of CFS—having the potential to contribute to the maintenance, or potential worsening of, fatigue and other physical symptoms (De Gucht, Garcia, den Engelsman & Maes, 2017). As such, they could hold potential for refining and improving interventions, and for reducing the distressing impact of CFS. Cognitive-behavioural therapy (CBT) is a treatment recommended by NICE (2007) for CFS. CBT aims to address cognitive and behavioural factors proposed to be perpetuating symptoms, such as ‘boom-and-bust’ activity and unhelpful beliefs related to CFS (Loades & Chalder, 2017). As illness perceptions could be a perpetuating cognitive factor, it may be that CBT interventions need to target these to be more effective (Wiborg, Knoop, Frank, & Bleijenberg, 2012). The CSM therefore has many implications for biopsychosocial assessment and intervention; however, there has been little investigation of illness perceptions in adolescents, so the extent to which the CSM is applicable in adolescents with physical health conditions remains to be tested.

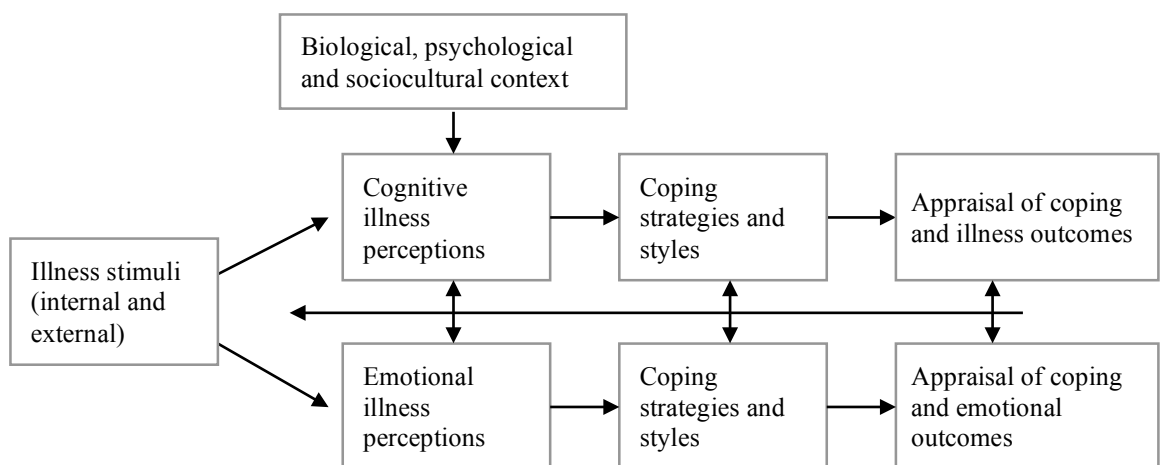


Figure 1. The Common-Sense Model of illness representation. Adapted from Diefenbach and Leventhal (1996).

One study focused on illness perceptions in young people with CFS (Gray & Rutter, 2007). Using the IPQ-R, young people were found to have identifiable perceptions of their CFS, which are linked to coping and outcomes. However, as there was no comparison group included, it is unclear if these findings are unique to young people with CFS or generalisable across physical health conditions. There are number of further limitations that weaken the validity and generalisability of the study’s

findings. Firstly, the age of participants was heavily skewed; only two of the 85 participants were under 14 years old, whilst 61 participants were aged between 17–25. Thus, a large proportion of the sample were young adults and findings are therefore not necessarily representative of adolescents with CFS. Gender was also skewed, with only five male participants. Although CFS is more common in females, prevalence studies indicate that 25% of children and young people with CFS are male (Lievesley et al., 2014), meaning males were underrepresented in the study. Further, as participants were recruited online via a self-help group, participants' diagnoses could not be verified. This method of recruitment also means that all participants were employing a particular coping strategy—again, limiting the generalisability of the findings. Further, depression was not measured in this study, despite a high comorbidity; at least 30% of young people with CFS are believed to have probable depression (Bould, Collin, Lewis, Rimes, & Crawley, 2013; Loades, Rimes, Ali, Lievesley, & Chalder, 2017), with depression scores found to be higher in those with CFS compared to arthritis (Brace, Smith, McCauley & Sherry, 2000). The tendency to make global, stable, internal attributions when depressed (Gladstone & Kaslow, 1995) could plausibly be linked to more negative illness perceptions so is an important variable to consider.

Research in adults, including those with CFS, has provided support for the CSM. However, it is less clear if the CSM assumptions hold true in adolescent populations. Given the developmental differences between adults and adolescents, differences in power dynamics and routes into services, it is not sufficient to generalise research from adults. Testing the applicability of the CSM in adolescents has implications for improving service provision, including psychological treatments.

The current study used a between-groups, cross-sectional design to compare illness perceptions across adolescents with CFS, juvenile idiopathic arthritis (JIA) and type 1 diabetes (T1D). JIA was chosen as a comparison group because it shares some similarities with CFS. It is idiopathic (like CFS) and there is an overlap in the nature of symptoms in CFS and JIA, with joint pain, stiffness and restricted movement featuring in both conditions (NICE, 2015). However, in JIA there are observable physical markers that facilitate diagnosis, such as swelling and restricted movement in joints (Bailey, 2014) and it is associated with less fatigue (Ali, Matcham, Irving & Chalder, 2017). T1D was chosen as a control group, as it is a physical health conditions with an identified physical cause and can be diagnosed with simple tests (NICE, 2015). Both JIA and T1D are associated with less stigma than CFS. Fatigue and physical functioning were measured to test to what degree illness perceptions could be accounted for by

these variables. Given the higher prevalence of depression in CFS than other physical health conditions (Ali et al., 2017), and the possible relationship with cognitive perceptions, depression was also measured. Similarly, anxiety was measured to test if any differences in illness perceptions could be explained by differences in anxiety levels.

Research questions

1. Are illness perceptions different in adolescents with CFS, compared to adolescents with other physical health conditions?
2. Are illness perceptions different in adolescents with CFS, compared to adolescents with other physical health conditions when accounting for fatigue, physical functioning, depression and anxiety?

Hypotheses

Based on the CSM and existing research in adults, we predicted that illness perceptions will differ in adolescents with CFS compared to JIA and T1D. Specific predictions based on Moss-Morris and Chalder's (2003) and Weinman et al.'s (1996) findings in adults with CFS, arthritis and diabetes are as follows:

1. Adolescents with CFS will report higher scores on identity, consequences and emotional responses subscales than adolescents with JIA and T1D.
2. Adolescents with CFS will report a less chronic timeline than adolescents with JIA and T1D
3. These differences in illness perceptions will remain when controlling for fatigue, physical functioning, depression and anxiety

The following predictions are also made regarding other variables:

4. In line with the defining characteristics of CFS and previous comparisons of adults with CFS and arthritis (Ali et al. 2017), it is predicted that adolescents with CFS will report higher levels of fatigue compared to adolescents with JIA or T1D.
5. Based on illness characteristics and comparison of adults with CFS and arthritis (Moss-Morris & Chalder, 2003) it is predicted that adolescents with CFS will report similar levels of physical functioning to adolescents with JIA, but lower than T1D.
6. Based on findings regarding the prevalence of depression in different physical health conditions (Ali et al., 2017; Bould et al. 2013), it is predicted

that adolescents with CFS will report higher depression scores than adolescents with JIA or T1D.

Method

Participants

Participants were recruited over 18 months between 2016–2018. CFS participants were age 12–18 years. T1D and JIA participants were age 11–17 years. Participants were required to be able to complete written questionnaires.

Of the participants recruited through clinics, 10 were excluded from analysis due to incomplete data (CFS=7; T1D=3). With online recruitment, a total of 92 responses were recorded. Of these, 15 were screened out for being outside the eligible age range, 44 did not progress past the information sheet and three were excluded due to incompleteness of the measures. Of the 30 participants who completed the study online, 16 stated they were from UK; eight from the USA; two from Canada; and one from Egypt, South Africa, Australia and Germany.

The final sample consisted of 130 participants, including 82 females (63%) and 48 males (37%). Mean age was 14.54 years (range 11–18; *SD* 1.91). See Table 2 for descriptive characteristics of sample and Figure 2 for flow diagram of recruitment.

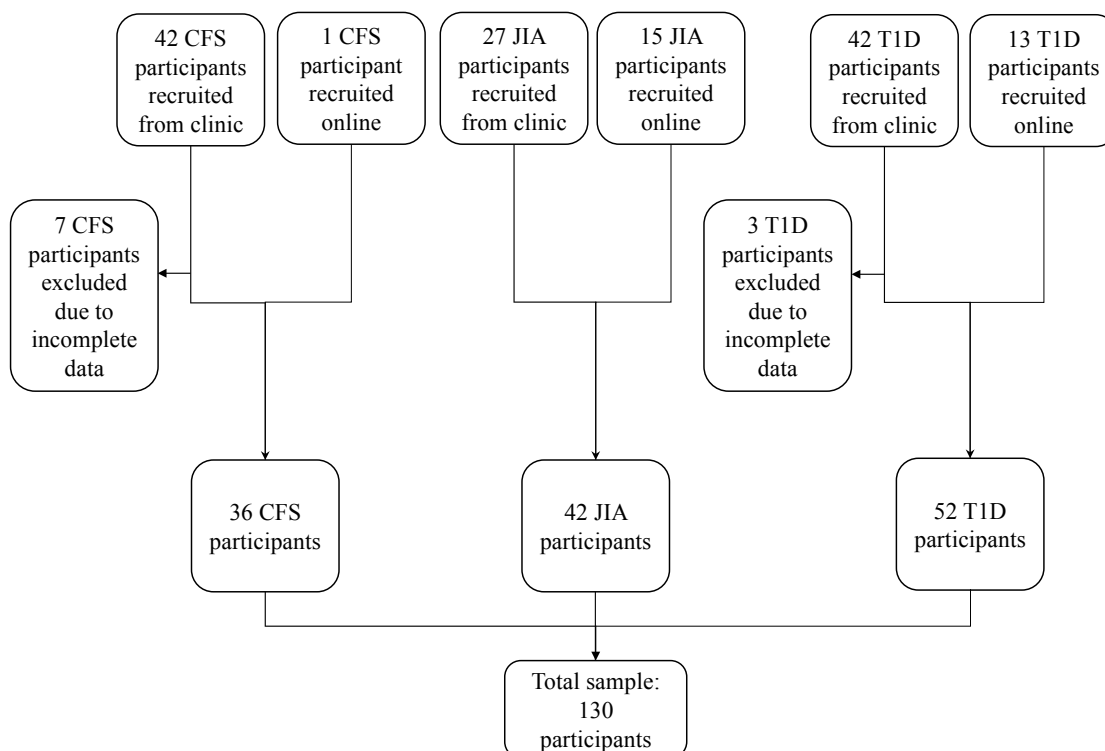


Figure 2. Flowchart of participant recruitment

Procedure

Clinic-recruited CFS participants were recruited from a specialist paediatric CFS team at the Royal United Hospital, Bath as part of a larger study. Participants were recruited following diagnosis, but prior to receiving intervention from the service. CFS diagnoses were confirmed according to NICE (2007) diagnostic criteria. Consent procedures and questionnaires were completed electronically via REDCAP, or pen-and-paper, depending on participant preference. Participants <16 years were required to gain consent from a parent / carer.

Clinic-recruited T1D and JIA participants were recruited through Bristol Children's Hospital. Diagnoses were confirmed by medical records prior to participation in the study. Eligible participants were invited to take part by researchers at outpatient clinic appointments. Consent procedures and questionnaires were completed electronically using the Qualtrics platform, administered on an iPad. Participants <16 years were required to gain consent from a parent / carer. Participants were left alone to complete the measures.

Participants were also recruited online; links to the online study (including online information sheets and consent forms) were posted in support groups on social media platforms and advertised online by National charities. Diagnoses were self-reported among these participants.

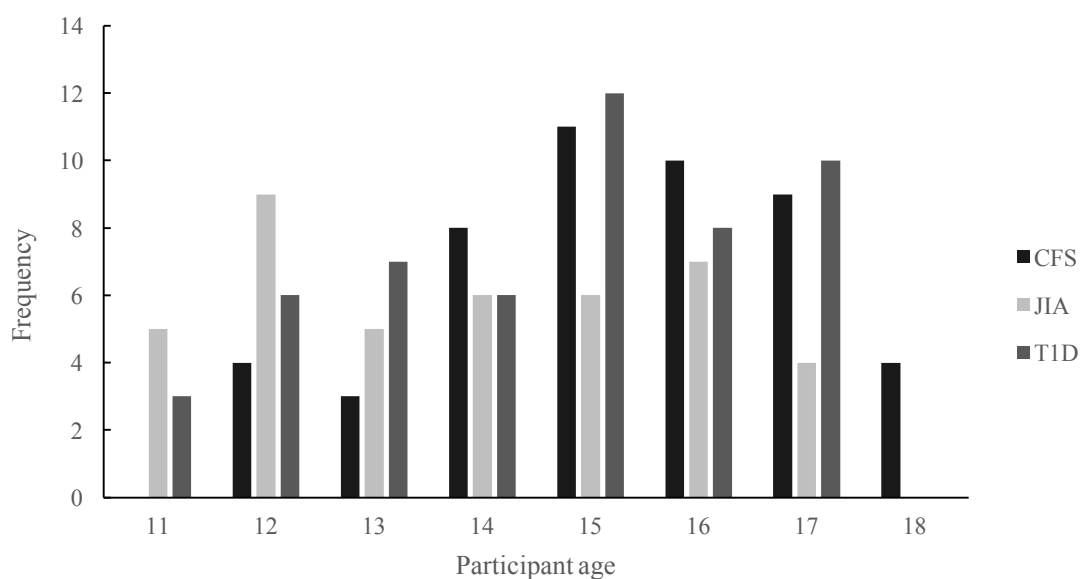


Figure 3. Distribution of participant age across the three conditions

Measures

Demographic information (age, gender, and country of residence for participants recruited online) was collected via self-report questions. For clinic-recruited CFS participants, medical comorbidities were recorded by the research team. These were screened for JIA and T1D. For all other participants, physical health conditions were self-reported via the online questionnaire.

Internal consistency for measures and subscales was calculated using Cronbach's alphas for each of the three conditions. See Table 1.

Illness perceptions. - Brief Illness Perception Questionnaire (BIPQ; Broadbent et al., 2006): a nine-item measure of cognitive and emotional perceptions of illness, with each measuring a different subscale. Eight items are rated on a 0–10 response scale: consequences (effect on life), timeline (expected duration), personal control (sense of control), treatment control (expected treatment effectiveness), identity (number and intensity of symptoms), concern, understanding and emotional response. The ninth item—cause—is open-ended, asking participants to list the three most important causal factors in their illness. The BIPQ has good to moderate concurrent validity with the longer IPQ-R (Pearson correlations between subscales: $r=.33-.63$, all $p<.001$; Broadbent et al., 2006), and has been found to have good validity and reliability in adults with a variety of illnesses (see Broadbent et al., 2006). The BIPQ has been previously used in adolescents with different physical health conditions (e.g. McGrady et al., 2010; Michel, Taylor, Absolom, & Eiser, 2010), but formal psychometric properties have not been reported for this age group.

Anxiety and depression. - Revised Children's Anxiety and Depression Scale (RCADS; Chorpita, Ebesutani, & Spence, 2011). This 47-item questionnaire measures: separation anxiety, social phobia, generalised anxiety, panic, obsessive compulsive, and depression. Items are rated on a four-point Likert-scale from 0=never to 3=always. Total anxiety and depression scores were used in this study. The RCADS has been found to have favourable construct and factorial validity (Chorpita, Moffitt, & Gray, 2005).

Physical Functioning. - 10-item physical functioning subscale of the 36-Item Short Form Health Survey (SF-36; Ware Jr & Sherbourne, 1992). Items are rated on a three-point scale from 1–3 (Ware Jr, Snow, Kosinski, & Gandek, 1993). Higher score indicates better physical functioning. High internal reliability of the subscale has been found in adults with CFS (Cronbach's $\alpha=.90$) and convergent validity is also good (Buchwald, Pearlman, Umali, Schmaling, & Katon, 1996). The physical functioning

subscale has previously been used in adolescents with CFS (e.g. Stulemeijer, de Jong, Fiselier, Hoogveld, & Bleijenberg, 2004) but has yet to be adequately validated.

Fatigue. - 11-item Chalder Fatigue Questionnaire (CFQ; Chalder et al., 1993).

This measure consists of two subscales: physical and mental fatigue. Each item has four response options: “less than usual”, “no more than usual”, “more than usual” and “much more than usual”. The measure has been validated in both clinical and non-clinical adult samples (Cella & Chalder, 2010) and has been used extensively in research with adolescents (e.g. Bould et al., 2013; Crawley & Sterne, 2009). Scoring can take the form of a bimodal system, or a Likert system. In this study, Likert scoring was used, with each item scored 0–3. High internal consistency has been found for the scale with Cronbach’s alpha=0.88–0.90 (Cella & Chalder, 2010).

Table 1. Cronbach’s alpha for subscales and overall measures

	RCADS: Depression subscale	RCADS: Anxiety subscale	RCADS: Overall score	SF-36: Physical functioning subscale	CFQ: Mental fatigue subscale	CFQ: Physical fatigue subscale	CFQ: Overall score
CFS	.85	.96	.96	.93	.80	.84	.89
JIA	.90	.95	.96	.94	.53	.84	.82
T1D	.93	.97	.98	.90	.66	.92	.89

Involvement of People with Personal Experience

A draft of the participant information sheets and consent forms were given to a young person’s advisory group at University Hospitals Bristol NHS Foundation Trust. Amendments were made to the content and layout based on their feedback.

Ethics

The data collection for T1D and JIA participants was approved by NHS Wales Research Ethics Committee 3 (reference: 16/WA/0378) and University of Bath Ethics Committee (reference 17-019). The data collection for CFS participants was approved by NHS Frenchay Ethics Committee (reference 16/SW/0136) and University of Bath Ethics Committee (reference 16-203). See Appendix F.

Data Analysis

Power calculations. A-priori power calculations were made using G*power to establish necessary sample size. The BIPQ has not previously been used to compare

illness perceptions in CFS and other conditions, so instead effect sizes were based on a study using the BIPQ to compare CFS participants with non-CFS fatigued participants (De Gucht, Garcia, den Engelsman, & Maes, 2016). See Appendix G. Post-hoc power calculations were also carried out, which suggested that the study was sufficiently powered.

Exclusions and missing data. Two online participants were excluded from analysis for having two of the physical health conditions of interest in this study. A further nine participants were excluded for missing data (CFS=7; T1D=2); all with ≥ 1 questionnaire missing. Where cases had $\leq 5\%$ of data missing, ($n=2$; both CFS) mean values were inputted for missing items (Roth, 1994). No items were missing from the BIPQ.

Statistical analyses. All analyses were carried out using SPSS version 24. First, the three conditions (CFS, JIA and T1D) were compared on demographic characteristics and potential predictor variables. Data screening indicated that variables largely did not meet assumptions of normality and homogeneity of variance, so non-parametric tests were used. All comparisons were made using two-tailed tests, with a Holm-Bonferroni corrected alpha. This controls the inflation of Type 1 error rate, while maintaining power (Ludbrook, 1998). Pearson chi-square was used for categorical variables (gender) and Kruskal-Wallis was used for continuous variables (age, physical fatigue, mental fatigue, physical health subscale, depression score and anxiety score). The data file was then split by condition and the same variables were examined within conditions, to compare clinic-recruited and online-recruited participants. Chi-square was used for gender and Mann-Whitney for the six continuous variables.

Qualitative responses for the cause subscale of the BIPQ were coded by (a) psychological (including stress or overwork); (b) risk factors (including genetics or diet); (c) immune causes (including virus); (d) chance (including an accident or bad luck); or (e) physical over-activity. Blank responses or “I don’t know” responses were not coded. As expected and observed counts were low within categories, percentages were compared. Conditions were then compared on each of the eight continuous-data BIPQ subscales using a series of Kruskal-Wallis tests. In the next stage of the analysis, a series of multiple hierarchical regressions were conducted with BIPQ subscales as the dependent variables. As the outcome variables showed indicators of heteroscedasticity and non-normally-distributed residuals, bootstrapping procedures were applied, with 1,000 trials. Bootstrapping is a robust statistical technique that does not rely on these assumptions (Wright, London, & Field, 2011). Independent variables were entered in

three blocks using the entry method. Gender and age were entered in the first block; physical fatigue, mental fatigue, physical functioning, depression score and anxiety score in the second block; and condition in the third block. Condition was dummy coded using T1D as the reference group.

As a further, exploratory analysis, illness perceptions were compared between depressed and non-depressed participants. This is presented as supplementary material (Appendix H).

Results

The three conditions (CFS=36; JIA=42; T1D=52) were compared across predictor variables. There was a significant effect of condition on gender, ($\chi^2(2, N=130)=9.05, p=.011$), age ($\chi^2(2, N=130)=9.04, p=.011$), physical fatigue ($\chi^2(2, N=130)=52.04, p<.001$), mental fatigue ($\chi^2(2, N=130)=46.86, p<.001$), physical functioning ($\chi^2(2, N=130)=30.97, p<.001$) and depression score ($\chi^2(2, N=130)=17.30, p<.001$) (see Table 2). There was no significant effect of condition on anxiety score. The difference in gender distribution between groups was followed-up with inspection of standardised residuals, which indicated that there was a significantly higher proportion of females in JIA group than expected. Standardised residuals were not significant in CFS or T1D groups. Remaining significant differences were followed up with Dunn-Bonferroni pairwise comparisons. CFS participants were significantly older than JIA participants ($p=.008$). There were no other differences in age. Physical fatigue was higher in CFS than both JIA ($p<.001$) and T1D ($p<.001$). Mental fatigue was also significantly higher in CFS than JIA ($p<.001$) and T1D ($p<.001$). Physical functioning was comparable across CFS and JIA participants, with T1D participants demonstrating significantly higher physical functioning than both ($p<.001$). Depression was significantly higher in CFS participants than JIA ($p=.002$) and T1D participants ($p<.001$).

No significant differences were found in predictor variables between online and clinic-recruited participants, except for physical functioning in JIA participants. JIA clinic recruited participants had higher physical health score (mean rank 25) than those recruited online (mean rank 16), indicating that those recruited from clinic had better overall health ($p=.033$). This did not remain significant when using the Holm-Bonferroni correction.

Between-group comparisons on BIPQ subscales identified significant differences in consequences ($\chi^2(2, N=130)=17.04, p<.001$), timeline ($\chi^2(2, N=130)=49.58, p<.001$), personal control ($\chi^2(2, N=130)=35.39, p<.001$), treatment

control ($\chi^2(2, N=130)=31.25, p<.001$), and understanding subscales ($\chi^2(2, N=130)=11.20, p<.001$). There were no significant differences in identity, concern or emotional response subscales. Pairwise comparisons indicated that illness consequences were rated as being greater in CFS participants than in JIA ($p<.001$) or T1D participants ($p=.002$). T1D participants rated their condition as having a longer timeline than JIA and CFS participants ($p<.001$), with JIA rating these items higher than CFS participants ($p=.01$). T1D participants also perceived more treatment control than JIA participants ($p=.015$) and CFS participants ($p<.001$), with JIA perceiving more treatment control than CFS participants ($p=.018$). T1D participants rated themselves as having more personal control than both JIA ($p<.001$) and CFS participants ($p<.001$), who did not significantly differ. Finally, understanding was significantly lower in CFS participants than T1D participants ($p=.003$); neither differed from JIA. See Table 3 for group comparisons.

Table 2. Sample characteristics and between-condition comparisons

	CFS (<i>n</i> = 37)		JIA (<i>n</i> = 42)		T1D (<i>n</i> = 52)		<i>P</i> value
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	
Male	18	(50%)	8	(19%)	22	(42.3%)	.011*
Female	18	(50%)	34	(81%)	30	(57.7%)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Age	15.22 ^a	(1.69)	13.86 ^b	(1.95)	14.58 ^{a,b}	(1.85)	.011*
Physical fatigue	17.17 ^a	(3.11)	10.38 ^b	(4.26)	9.12 ^b	(4.91)	<.001*
Mental fatigue	8.31 ^a	(2.38)	4.88 ^b	(1.80)	4.31 ^b	(2.22)	<.001*
Physical functioning	20.47 ^a	(5.37)	21.98 ^a	(5.86)	26.52 ^b	(3.93)	<.001*
RCADS Depression	15.78 ^a	(5.30)	10.52 ^b	(5.99)	10.23 ^b	(7.36)	<.001*
RCADS Anxiety	37.44 ^a	(20.99)	30.88 ^a	(18.12)	32.33 ^a	(23.97)	.354

RCADS, Revised child anxiety and depression scale; *M*, mean; *SD*, standard deviation

Shared superscripts denote no significant differences

*significant using Holm-Bonferroni adjusted *p*-values

Comparison of categorised responses for the cause subscale showed CFS participants were most likely to attribute cause of illness to psychological causes (55% of responses), followed by immune causes (27%). In contrast, JIA and T1D participants were most likely to attribute cause of illness to risk factors (49 and 63%, respectively), followed by immune causes (27 and 18% respectively), as well as chance in T1D (also 18%).

Table 3. Between-condition comparisons on BIPQ subscales

	CFS <i>n</i> = 37		JIA <i>n</i> = 42		T1D <i>n</i> = 52		<i>P</i> value
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Consequences	7.67 ^a	(1.62)	5.93 ^b	(2.08)	6.15 ^b	(2.15)	<.001*
Timeline	6.03 ^a	(1.78)	7.50 ^b	(2.58)	9.38 ^c	(1.59)	<.001*
Personal control	2.92 ^a	(2.01)	3.95 ^a	(2.16)	5.87 ^b	(1.96)	<.001*
Treatment control	5.22 ^a	(2.21)	6.88 ^b	(2.26)	8.15 ^c	(2.36)	<.001*
Identity	7.06 ^a	(1.90)	5.90 ^a	(2.22)	6.04 ^a	(2.36)	.078
Concern	6.14 ^a	(2.40)	5.74 ^a	(2.43)	5.19 ^a	(2.82)	.263
Understanding	6.81 ^a	(1.98)	7.64 ^{a, b}	(2.54)	8.19 ^b	(1.93)	.004*
Emotional response	6.56 ^a	(2.68)	6.43 ^a	(2.67)	6.04 ^a	(2.92)	.679

Shared superscripts denote no significant differences.

*significant using Holm-Bonferroni adjusted *p*-value

Bootstrapped multiple regressions demonstrated that, after controlling for age and gender, predictor variables (mental fatigue, physical fatigue, physical functioning, depression and anxiety) made a significant improvement to the amount of variance explained when consequences, timeline, personal control, treatment control, identity and emotional response were entered as the outcome variable. Entering condition at step 3 significantly improved the model for timeline, personal control and treatment control as outcome variables. JIA vs T1D was a significant predictor in the consequences dimension, and CFS vs T1D was a significant predictor in the understanding dimension. The final models at step 3 explained 36.7% of the total variance in the timeline dimension, 31.9% of variance in perceived personal control and 25.6% of variance in perceived treatment control. See Table 4.

Table 4. Table 4. Results of hierarchical multiple regression analyses with BIPQ subscales as outcome variables

Predictors	Consequences	Timeline	Personal control	Treatment control	Identity	Concern	Understanding	Emotional response
	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)	B (SE)
Step 1								
Female gender	0.47 (0.33)	0.69 (0.34)*	-0.32 (0.43)	0.16 (0.47)	-0.15 (0.42)	0.11 (0.51)	0.67 (0.44)	0.70 (0.52)
Age	0.13 (0.09)	0.06 (0.10)	0.07 (0.11)	0.07 (0.12)	0.33 (0.12)**	0.22 (0.13)	0.13 (0.11)	0.14 (0.12)
<i>R</i> ² change	.060*	.019	.011	.000	.088**	.044	.025	.070**
Step 2								
Physical fatigue	0.05 (0.06)	-0.13 (0.06)*	0.01 (0.06)	-0.02 (0.07)	0.01 (0.06)	0.07 (0.08)	0.02 (0.07)	0.08 (0.07)
Mental fatigue	0.11 (0.09)	0.12 (0.09)	0.10 (0.11)	0.21 (0.10)*	-0.06 (0.10)	0.07 (0.15)	-0.05 (0.13)	0.00 (0.13)
Physical functioning	-0.12 (0.03)***	-0.04 (0.04)	0.05 (0.05)	0.06 (0.04)	-0.10 (0.04)**	0.05 (0.05)	-0.05 (0.05)	0.03 (0.05)
Depression score	0.04 (0.05)	0.15 (0.05)**	-0.10 (0.05)*	-0.08 (0.05)	0.09 (0.05)	-0.05 (0.07)	-0.04 (0.08)	0.11 (0.06)
Anxiety Score	-0.01 (0.01)	-0.02 (0.01)	0.00 (0.01)	-0.10 (0.02)	-0.03 (0.01)	0.03 (0.02)	-0.01 (0.02)	0.03 (0.02)
<i>R</i> ² change	.279***	.162***	.229***	.204***	.126**	.065	.060	.219***
Step 3								
Condition								
T1D	Reference	Reference	Reference	Reference	Reference	Reference	Reference	Reference
JIA	-0.92 (0.42*)	-2.16 (0.48)***	-1.61 (0.46)***	-1.09 (0.47)*	-0.37 (0.52)	0.86 (0.59)	-0.82 (0.52)	0.38 (0.56)
CFS	-0.31 (0.54)	-3.71 (0.50)***	-2.68 (0.59)***	-2.82 (0.66)***	-0.10 (0.53)	0.42 (0.84)	-1.41 (0.64)*	-0.68 (0.66)
<i>R</i> ² change	.028	.230***	.127***	.103***	.004	.015	.040	.012
<i>Overall adjusted R</i> ²	.319	.367	.319	.256	.160	.059	.060	.248

Note. All regression coefficients are from the final step in the analyses. Standard errors and significance values based on 1000 bootstrapped samples.

* $p < .05$, ** $p < .01$, *** $p \leq .001$

Discussion

This study investigated the assumption, based on the CSM, that illness perceptions differ across adolescents with different physical health conditions. The results revealed significant differences across adolescents with CFS, JIA and T1D. Adolescents with CFS perceived greater consequences, a less chronic timeline, and lower treatment control than adolescents with JIA or T1D, and less understanding of their condition than adolescents with T1D. Adolescents with CFS and JIA reported less personal control over their illness than adolescents with T1D. With the exception of the consequences subscale, these findings remained consistent when controlling for age, gender, fatigue, physical functioning, anxiety and depression. As predicted, CFS participants reported significantly higher physical and mental fatigue than JIA and T1D participants. Comparable levels of physical functioning were found between CFS and JIA participants using the SF-36 subscale, while T1D participants reported higher physical functioning. Depression scores were higher among CFS participants compared to JIA and T1D. No significant differences were found in anxiety.

The finding that illness perceptions differed across conditions supports the overall hypothesis that illness perceptions in adolescents with CFS are distinct from other physical health conditions. This is consistent with research with adults (Dickson, Toft, & O'Carroll, 2009; Moss-Morris & Chalder, 2003) and provides preliminary evidence for the validity of the CSM in adolescents with physical health conditions. As predicted, higher consequences were reported in CFS participants—attesting to the severe functional impairment associated with CFS in adolescence (Crawley et al., 2011; Garralda & Rangel, 2004). This is also consistent with research with adults (Moss-Morris & Chalder, 2003; Wiborg et al., 2012). (Butler, Chalder, & Wessely, 2001; Moss-Morris & Chalder, 2003) Inconsistent with the prediction, and in contrast to research with adults, no differences in illness identity were found across conditions. Thus, adolescents with CFS reported the condition impacts their life more severely than JIA and T1D, despite reporting a similar number and severity of symptoms and despite similar levels of physical functioning to JIA participants.

In contrast to prediction, no difference was found in ratings of emotional responses to illness across conditions. This is somewhat surprising given the uncertainty associated with CFS, participants' ratings of the severe impact on life and the finding that depression scores were higher in participants with CFS. Given that CFS participants were most likely to attribute the cause of their illness to psychological factors, it is possible that adolescents with CFS are more likely to view CFS as a

consequence of psychological difficulties, rather than the other way around. However, qualitative interviews with adolescents with CFS and depression found that most felt CFS predated depression (Taylor, Loades, Brigden, Collin, & Crawley, 2017). It is also possible the higher depression scores in CFS participants are reflective of the overlap in symptoms. The relationship between mood, CFS and illness perceptions warrants further research.

The finding that CFS was associated with lower perceived control suggests that there is an aspect of having CFS, not accounted for by fatigue and physical functioning, that is influencing this illness perception. A possible explanation is that the lack of established aetiology of CFS, lack of clear medical treatment, and the associated uncertainty may contribute to participants' diminished sense of control. According to the CSM, these differences in illness perceptions have implications for coping responses and illness management, as well as medical and psychological outcomes (Petrie et al., 2007). Meta-analyses have found that higher perceived control is consistently associated with better outcomes, such as greater physical functioning, role functioning and psychological wellbeing, and lower distress and disease state (Hagger, Koch, Chatzisarantis, & Orbell, 2017; Hagger & Orbell, 2003). Higher perceived control is also associated with cognitive reappraisal, problem-focused and social support-seeking coping strategies, whereas lower perceived control is associated with avoidance. A systematic review of interventions targeting illness perceptions found that perceived control most frequently shifted (Broadbent et al., 2015), suggesting that perceived control is amenable to change. Indeed, an increased sense of control has been hypothesised as being an important mediator for treatment outcomes in CBT for CFS (Wiborg et al., 2012).

The perception of a less chronic timeline in CFS participants compared with JIA and T1D supports the hypothesis and is consistent with previous research with adults (Dickson et al., 2009; Moss-Morris & Chalder, 2003). This is suggestive of beliefs/hopes for recovery in adolescents with CFS, but as perceived control is low, this indicates that participants are attributing their anticipated recovery to factors outside of their control. Findings from wider literature on the relationship between perceived timeline and coping/outcomes is mixed. While some have found reported chronic timeline to be associated with worse outcomes (Broadbent et al., 2015; Hagger & Orbell, 2003), Hagger et al. (2017) found some evidence that reported chronic timeline had an indirect effect of *higher* physical functioning, social functioning and wellbeing, with lower distress and disease state, mediated by problem-focused generic coping. It is

possible that in some cases, perceiving a health condition as less chronic reduces motivation to engage in adjustment to the condition. Future research would benefit from examining these relationships specifically in adolescents with CFS.

Limitations

There are several limitations to this study, which should be accounted for in the interpretation of the findings. Participants were recruited from clinics using convenience sampling, which limits generalisability. As these participants were accessing specialist services, it is not clear to what extent these findings generalise to participants treated in primary care, or too unwell to access specialist services. It does, however, allow verification of diagnoses, whereas diagnoses in online-recruited participants were self-reported and not clinically verified. This is of particular significance for the CFS participant who took part online, given the exhaustive and specialist testing required to diagnose CFS. In addition, participants recruited from services and online may be utilising different coping strategies, with implications for illness perceptions. Thus, the results could be biased towards individuals with certain illness perceptions, coping strategies and physical health outcomes. The finding of no differences between online and clinic-recruited T1D and JIA participants on predictor variables is encouraging with regards to generalisability, but this will need to be further investigated in the future.

There was an overrepresentation of females in the T1D and JIA samples in comparison to other studies (Packham & Hall, 2002; Soltesz, Patterson, Dahlquist, & Group, 2007). In contrast, the gender distribution in the CFS sample was equal, whereas CFS is believed to affect females disproportionately by 3:1 (Lievesley et al., 2014). This raises questions regarding the representativeness of the samples.

The eligible age range for participants varied slightly across groups, which is partly a result of differences in access between the specialist services. Groups were unmatched on demographic factors, including age, where CFS participants were older than JIA participants. However differences in demographic factors were controlled for in the regression analyses. Despite the older age of CFS participants, younger adolescents were better represented in the current study than in Gray and Rutter's (2007) research on young people with CFS, thus, providing preliminary evidence for individuals in this age group.

A further limitation is that duration of illness was not accounted for in this study, which could have differed across conditions. This is an important variable to consider in future research, as the CSM proposes that longer illness duration is associated with

more opportunity for appraisal of coping and illness management, which may lead to amendment of illness perceptions.

Although the measures used in this study have previously been used in research with adolescents, the CFQ and SF-36 physical functioning subscale have yet to be adequately validated in the populations in this study. Cronbach alphas indicate good internal consistency, with the exception of mental fatigue, which was problematic in the JIA and T1D participants.

Finally, it is important to remember the complexity of the relationship between physical and psychological variables when conducting studies in those with physical health conditions; according to the CSM, physical variables can be both illness outcomes and the internal stimuli that contribute to illness perceptions. Thus, there is not a simple linear causality when studying the role of psychological variables.

Implications

The preliminary support from this study for the validity of the CSM in adolescents suggests that cognitive illness perceptions are important to consider as part of a biopsychosocial assessment, formulation and treatment of adolescents with physical health conditions.

CBT is the evidence-based treatment recommended by NICE (2007) to improve outcomes in adolescents with CFS; evidence shows that with specialist treatment, up to two thirds of young people recover from CFS (Lloyd, Chalder, & Rimes, 2012; Nijhof, Bleijenberg, Uiterwaal, Kimpen, & van de Putte, 2012; Nijhof et al., 2013). However, the precise mechanisms of change in CBT for CFS are unclear; a better understanding of these mechanisms may improve the efficacy. Illness perceptions have previously been identified as an important target for CBT for adults with CFS (Wiborg et al., 2012) and the findings from this study provide some evidence for specific illness perceptions to target in adolescents with CFS. The lower perceived control found in CFS participants is likely to impact engagement with CBT; CBT requires collaborative engagement and a sense of self-efficacy; it is necessary that adolescents believe the treatment being offered can support them to develop the skills required to bring about change (Stallard, 2005). This suggests that psychoeducation, socialisation to CBT as a form of treatment (and its effectiveness) and interventions aimed at improving self-efficacy may be important components to be delivered early in contact with services. Similarly, while the lower perceived understanding in CFS participants reflects a poorer

medical understanding of the aetiology, this highlights the importance of giving service users the most up-to-date knowledge and research that we have access to.

Future Research

The inclusion of participant youCFS sample in this study contained a higher proportion of young adolescents compared to Gray and Rutter's (2007) study and no participants over 18 years. Future research would benefit from recruitment of larger samples from a range of settings to increase generalisability. Longitudinal designs would allow investigation of the relationship between illness perceptions, coping strategies and outcomes over time. Intervention studies for adolescents with CFS should consider including a measure of illness perceptions to track changes and their relationship to other treatment outcomes.

Conclusions

This study found that adolescents with CFS differ in their illness perceptions compared to adolescents with other physical health conditions, thus providing initial evidence for the applicability of CSM in this population. In particular, CFS participants reported lower perceived control, a less chronic timeline and less understanding of their illness. This is likely to have implications for the coping strategies used and the readiness to engage with evidence-based treatments. Interventions should consider explicitly targeting these perceptions to optimise outcomes. Future research should monitor the impact of intervention on illness perceptions.

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Executive Summary

Background

Chronic Fatigue Syndrome (CFS) is a physical health condition characterised by prolonged, debilitating and unexplained fatigue, alongside other symptoms than can include cognitive, sleep and musculoskeletal problems. The cause of CFS is not fully understood, but genetic factors, viral infection, immune and endocrine factors, stress, illness perceptions, psychiatric mechanisms and activity levels have all been named as potentially being involved in its onset and maintenance in adolescents. There is considerable functional impairment associated with CFS in adolescence; for example, it is the biggest cause of long term sickness from school.

As CFS is not well understood, it can only be diagnosed after exhaustive tests to rule other potential causes out. As a result, adolescents with CFS report feeling disbelieved about their condition, uncertainty around their future and concerns about how to explain it to others. Research has identified that individuals with CFS often feel stigmatised by others, including health professionals. The experience of having CFS is therefore different to a lot of other physical health conditions.

The ‘common-sense model’ of illness representations proposes that individuals have cognitive and emotional perceptions about their illness, based on their illness experience, which encompasses somatic sensations, personal and social beliefs and information from others. These illness perceptions guide coping strategies and illness management, and influence medical, psychological and behavioural outcomes. More negative illness perceptions are associated with increased disability, slower recovery and poorer quality of life. The common-sense model has been tested in adults with a wide range of physical health conditions, but its testing on adolescents has been very limited.

Due to the distinct illness experience in CFS, illness perceptions are of particular interest. One study found that adults with CFS had more negative perceptions of identity and consequences than adults with rheumatoid arthritis, despite comparable levels of disability. It has been suggested that illness perceptions need to be targeted within CBT for CFS. However, illness perceptions in adolescents with CFS have not been properly tested.

Aims

The aim of this study was to test the applicability of the common-sense model in adolescents by finding out if illness perceptions in adolescents with CFS were different to illness perceptions in adolescents with Juvenile Idiopathic Arthritis (JIA) and Type 1 Diabetes (T1D). JIA shares some features with CFS (pain, physical fatigue, unknown cause), but it is also easier to diagnose and is associated with less stigma. T1D has an identified physical cause and can be diagnosed with a simple test.

Method

Adolescents (aged 11–18) were recruited with either CFS, JIA or T1D. Adolescents were asked to fill in questionnaires about their illness perceptions, anxiety, depression, fatigue and physical functioning. Illness perceptions were measured using the Brief Illness Perceptions Questionnaire (BIPQ) which consists of nine components: consequences (perceived effect on life), timeline (expected duration), sense of personal control, treatment control (expected treatment effectiveness), identity (number and intensity of symptoms), concern, understanding, emotional response and cause. Scores on each of the illness perceptions scales were then compared. Final analysis consisted of 130 adolescents: CFS=37; JIA=42; and T1D=52.

Results

Illness perceptions were found to be significantly different between conditions. Adolescents with CFS reported greater perceived consequences, a less chronic timeline and lower treatment control than adolescents with JIA or T1D, and less understanding of their condition than adolescents with T1D. Adolescents with CFS and JIA reported less personal control over their illness than adolescents with T1D. With the exception of the consequences subscale, these findings remained consistent when controlling for age, gender, fatigue, physical functioning, anxiety and depression.

Implications

The results from this study provide preliminary evidence supporting the validity of the common-sense model in adolescents. This suggests that illness perceptions may be important in the assessment, formulation and treatment of adolescents with physical health conditions.

CBT is an evidence-based treatment for CFS. However, CBT requires self-efficacy—a belief that the treatment being offered can support them to develop the

skills required to bring about change. The findings of lower perceived control in adolescents with CFS in this study suggests that psychoeducation, socialisation to the model (and its effectiveness) and interventions aimed at improving self-efficacy may be important components to be delivered early in CBT for CFS.

To further our understanding, it would be beneficial for intervention studies for CFS to include measures of illness perceptions in order to track changes and their relationship to other outcomes.

Connecting Narrative

Within this connecting narrative, I will reflect on the process of completing my main research project, service improvement project, critical review of literature and five case studies. I will reflect on some of the challenges I have faced along the way, as well as some of the learning I have derived as a result.

Main Research Project

Study selection and development. At the beginning of the course, at the time of project development, I knew I wanted my main research project to be with children and young people. However, with no previous experience of working in child services, I found difficult to identify specific research gaps to fill. I therefore relied, to an extent, on supervisors and other clinicians to provide some potential directions. After a few discussions, meetings and initial ideas, Dr Maria Loades introduced me to the area of illness perceptions. I was interested by this topic, but it was not something I had prior knowledge of. I therefore needed to do extensive reading of relevant literature to familiarise myself with the area and develop a meaningful research question, which I did in collaboration with Maria. To begin with, I related to my research question in quite an academic way. I could see how it contributed to the literature, but I sometimes found it harder to see the genuine clinical utility. However, over the course of training I was able to consider the research area in relation to the teaching we received and to my clinical experiences on placement, which made the research question seem less abstract and more clinically meaningful. This has helped me to mentally bridge the gap between research and clinical practice. In the future, I hope to be able to develop research questions based on gaps evident from clinical practice.

Ethical approval. I faced several challenges throughout this project. One of the main challenges related to the ethics process. I was aware that receiving ethical approval for research can be time-intensive and so I worked hard to complete my NHS ethics application and submit it as early on in training as I could—just as the second year of training began. I found the IRAS ethics application form to be cumbersome and the process of completing it made me reflect on how inaccessible it must be for many clinicians outside of academia to complete. There seems to be a certain conflict between encouragement from Trusts for clinicians to be more involved in research, and the inaccessible processes that are required. I am thankful that I submitted my NHS ethics

application at an early stage, as it meant I had enough time to overcome barriers that arose. There is, understandably, extra precaution regarding ethics of research involving children. As such, following my research ethics committee panel meeting, it was decided that the consent process for my study should be amended so that information sheets could be read by potential participants prior to their attendance at the clinical appointment where they would be invited to take part. Having made these amendments, it later became clear that this was something the hospital was unable to accommodate and recruitment was therefore unable to begin. I found this frustrating and I felt helpless, as during this period there was very little I could do to move forward with the project and there were clinics of potential participants that could not be invited to take part in the research because of this barrier. As a result, it was necessary to demonstrate to the committee that this requirement was stalling recruitment and to evidence that there was similar research operating in the service without this requirement that was ethically sound. Eventually, I was granted an amendment that meant sending information sheets was not required. This highlighted an advantage of being familiar with other local research designs and procedures, but also in being able to use robust reasoning to challenge decisions.

Recruitment and data collection. Once recruitment could begin, it became obvious that the two teams I was recruiting from were very different in their set-ups, which had a significant bearing on recruitment. Whereas most patients seen in the Paediatric Diabetes service have Type 1 Diabetes (and were therefore eligible to participate), patients with Juvenile Idiopathic Arthritis are seen under Paediatric Rheumatology, which encompasses a wide range of health conditions. It became apparent that there was no simple way of identifying eligible participants within the Rheumatology service, which posed a real challenge for recruitment. As one of my placements was situated in Bristol Children's Hospital I was able to support this process by manually checking clinic lists for eligible participants. However, a further challenge was identifying professionals who could invite potential participants to take part. As a result, a lot of the data collection was done by myself, which had not been part of the original planned procedure. Despite these difficulties, there were several healthcare professionals who were very supportive throughout this process and facilitated me being able to approach potential participants.

The recruitment process taught me several things that I will take forward to any future involvement in research. For example, I can see how having a physical presence within the service made it possible to recruit many more participants than would have

been possible otherwise; developing positive relationships with other team members was integral to this process. Being embedded in the relevant service therefore seems an important factor in the success of recruitment. I can also see the value of developing a research contract so that it is clear what the expectations are for all stakeholders and so this can be reviewed throughout the research journey. As the practicalities of recruiting proved more difficult than was anticipated at the design stage, I can see real value in doing a 'process walkthrough' where the intricacies of the recruitment process are considered.

Despite the challenges, I found it rewarding to see the project develop from conceptualisation, through data collection, analysis and write-up.

Service Improvement Project

Study selection and development. I initially intended for my Service Improvement Project to take place in the service where my first clinical placement was. My proposal was approved, but further development and implementation of the project proved difficult, not least because the service underwent several big changes and a series of team members left the service. I had prioritised my main research project and critical review of the literature and so the service improvement project was the last one to make headway on. Although I had done a lot of work towards the planning of this project, I felt the service context it made it too difficult and too risky to continue with the project and I made the decision to take forward a different project instead. At the time, I felt worried at having no service improvement project at such a late point in training, but I also felt motivated to get stuck into a project and make progress. I contacted a field supervisor at Great Western Hospital who shared some initial ideas of areas to focus on within the service. The prospect of evaluating supervision groups excited me, as it is an area where I was keen to learn more about the evidence base, so I was pleased to take on this project. I formed research questions based on the needs of the service, but also brought in theoretical underpinnings from wider literature.

Recruitment and data collection. After developing the design for the project, I relied on my field supervisor, Leah, to administer, collect and return questionnaires to me to analyse and develop into focus group questions. Her input was also needed to support the arrangement of the focus group. I was limited in what I could do from afar, so I felt grateful that Leah delivered on what she had agreed to do, especially given how busy I know she was. I was aware throughout this project of my position as a trainee clinical psychologist and how this might influence participants' ability to be honest with

me about their experiences of having supervision with a clinical psychologist. This was thought about carefully and we made several steps along the way to reassure participants about the anonymity process. Throughout the focus group, participants were very positive about the supervision they received. I found it heartening to hear this and it made me reflect on my role as a supervisor in the future. However, I did also have initial concerns about how I could use this data to be of help to the service.

Data analysis. I was glad to have the opportunity to undertake qualitative analysis, as this is not something I had not previously done. Through wider reading, I came across lots of criticism aimed at the way qualitative research is often conducted. This increased my determination to conduct a robust and methodologically sound project. However, my lack of experience meant a steep learning curve in the analysis process. I found the inherent subjectivity of thematic analysis unsettling and doubted my ability to make sense of the data without a framework to follow. The analysis process was therefore very time intensive and I developed and changed themes several times. I found peer debriefing helpful and reassuring and I could certainly see the value of this in increasing ‘trustworthiness’ of the results.

Conducting this project gave me first-hand experience in some of the advantages of using qualitative methodologies. The results included details from participants that it would not have been possible to collect with quantitative methodologies only.

Critical Review of Literature

Study selection and development. I initially found it difficult to identify a question for a literature review. Through discussions with Dr Maria Loades, the research area of HIV in young people was suggested. This represented an opportunity to learn more about an area I had no prior knowledge about. The aspect of the review that appealed to me most was the opportunity to be involved in cross-cultural research, with the potential to have an impact in an area of the world with limited resources. However, this also presented challenges in that I was unfamiliar with the environmental context of the research. This made me realise the benefit of personal and professional experience for making sense of research findings. Instead, I was reliant on guidance from my supervisors and immersing myself in additional literature to meaningfully interpret the data (e.g. to identify relevant variables missing from the studies included in the literature review).

Analysis. I was disappointed that so few eligible studies were found for my literature review; this was a surprise to me and both my supervisors. It was further

disappointing that authors did not supply relevant data from their datasets when contacted. Furthermore, given that several studies focused on the relationship between childhood depression and having a family member with HIV, it seemed like an oversight not to include childhood HIV status as a variable.

Despite the fact that so few eligible papers were returned, the systematic review ended up being very time-intensive. The nature of the included papers were exploratory, cross-sectional designs with high numbers of variables and this provided challenges in synthesising the results. It was also necessary to adapt existing quality assessment tools to make one appropriate for the type of studies. As I undertook the literature review at an early stage in training, I was not able to benefit from peer learning during this process and instead felt that I was having to find my own way. This was in contrast to my service improvement project, where I felt I was able to benefit from my colleagues' learning experiences of conducting qualitative analyses.

I found the process of critiquing papers valuable for considering my own research, in terms of methodology, analysis and reporting of results.

Case Studies

Completing case studies on each placement has helped me to link clinical practise to theory and has encouraged me to use outcome monitoring. I often found the writing-up of case studies a helpful tool for explicitly articulating hypotheses, rather than holding them implicitly in mind. Similarly, case studies were an effective prompt to consider the reasons for each intervention, for thinking clearly about change mechanisms and for monitoring changes.

Overall Reflections

It has been challenging to juggle so many different research projects alongside clinical placement. However, I feel well equipped to conduct research post-qualification and hope that being embedded in a service and identifying research gaps through clinical working will stand me in good stead to continue research practice.

Acknowledgements

I would like to everybody who has supported me over the last three years. I would particularly like to thank Dr Maria Loades—my primary supervisor for two projects. I am very grateful to Maria for always making herself available to me, for always being approachable, and for her (very) timely responses. I am also grateful to Maddy, Claire, Sangeeta, Rachel, Kate the physio and the rheumatology nurses for their support with data collection.

Thank you to my parents for their support and encouragement prior to and during training. And of course, thanks to Ben for putting up with me, for supporting me, and for keeping me well stocked with food and Rooibos tea.

Appendices

APPENDIX A. Quality assessment tools (systematic review)

Quality assessment tool for assessing studies examining risk factors for depression

Representativeness

1. *What kind of recruitment strategy has been used?*
Randomised/consecutive (2); Non-randomised/convenience (0); Not stated (0)

Eligibility Criteria

2. *Have eligibility criteria been specified?*
Yes (1); No (0)

Sample Size

3. *Is the sample size justified?*
Justified and satisfactory (1) Not justified (0)
4. *What is the sample size?*
≤149 (0); 150-399 (1); 400+ (2)

Participation rate

5. *Is the participation rate reported?*
Reported and over 75% (2); Reported and under 75% (1); Not reported (0)

Criteria for Depression

6. *How has depression been detected?*
Clinical interview (2); Screening tool validated for use in Southern Africa (1); Other screening tool (0)

Criteria for HIV

7. *How has HIV status been ascertained?*
Clinically verified (1); Self-report, carer-report, or method not reported (0)

Ascertainment of risk factors

8. *Were potential risk factors measured using validated measurements?*
[Not scored, but variables divided into 3 categories: i) using tool validated for use in Southern Africa; ii) not validated in South Africa but available or described; iii) no description of measurement tool]

Confounding factors

9. *Were age, gender and recruitment location controlled for (where appropriate)?*
Yes (1); No (0)

Statistical test:

10. *Were the statistical tests used to analyse the data appropriate and clearly described?*
Data analysis process is well-described, complete, and statistic methods used are robust and appropriate (2); Statistical methods are generally adequate, but some details of data analysis process missing (1); Statistical methods are not appropriate, not described or incomplete (0)

Reporting of results

11. *Was the reporting of results complete?*
Reporting of p values, confidence intervals, mean and SD/range for continuous variables (1); Reporting is incomplete (0)

Total = /16

Quality assessment tool for assessing interventions for depression in HIV-infected youth

Representativeness

1. *What kind of recruitment strategy has been used?*
Randomised/consecutive (2); Non-randomised/convenience (0); Not stated (0)

Eligibility Criteria

2. *Have eligibility criteria been specified?*
Yes (1); No (0)

Sample Size

3. *Is the sample size justified?*
Justified and satisfactory (1) Not justified (0)

Participation rate

4. *Is the participation rate reported?*
Reported and over 75% (2); Reported and under 75% (1); Not reported (0)

Criteria for Depression

5. *How has depression been detected?*
Clinical interview (2); Screening tool validated for use in Southern Africa (1); Other screening tool (0)

Criteria for HIV

6. *How has HIV status been ascertained?*
Clinically verified (1); Self-report, carer-report, or method not reported (0)

Allocation to condition

7. *Were study participants randomised to intervention/comparison groups?*
Yes (1); No (0)

Intervention

8. *Was the intervention(s) clearly described?*
Yes (1); No (0)

Assessment of outcome

9. *Was an attempt made to blind those measuring the main outcome (depression) of the intervention?*
Yes (1); No (0)

Confounding factors

10. *Were age, gender and recruitment location controlled for (where appropriate)?*
Yes (1); No (0)

Follow up

11. *Was the follow-up considered?*
Follow-up rates reported (1), Not (0)

Statistical test:

12. *Were the statistical tests used to analyse the data appropriate and clearly described?*
Test is clearly described and appropriate (2); Test is acceptable (1); Test is not appropriate, not described or incomplete. (0)

Reporting of results

13. *Was the reporting of results complete?*
Reporting of p values, confidence intervals, mean and SD/range for continuous variables (1); Reporting is incomplete (0)

Total = /17

APPENDIX B. Analysis of dataset (systematic review)

Provided by (Målqvist et al., 2016).

Data for participants aged ≤ 19 years:

HIV status	Total sample (<i>n</i>)	Scoring 13+ on EDPS (<i>n</i>)	Scoring 13+ on EDPS (%)	<i>P</i> -value
Negative	135	13	9.63%	0.007**
Positive	31	18	58.06%	
Total	166	31	18.67%	

**, significant to $< .01$ level

Analysis for HIV+ participants only:

	Depressed (<i>n</i>)	Non-depressed (<i>n</i>)	Total (<i>N</i>)	<i>P</i> -value
<u>Mother's education</u>				
Secondary +	7	10	20	0.684
Primary	1	1		
None	0	1		
<u>Marital status</u>				
Married / living	3	1	30	0.17
Single	10	16		
<u>Employment</u>				
Employed	1	1	30	0.765
Unemployed	11	17		
<u>Housing</u>				
Homestead	5	2	22	0.047*
Tenant	4	11		
<u>Water source</u>				
Tap	5	13	30	0.058
Communal	4	5		
Surface	3	0		
<u>Sanitation</u>				
Pit latrine or no toilet	10	16	30	0.661
Flush toilet	2	2		
<u>Sharing toilet</u>				
Yes	7	8	23	0.673
No	3	5		
<u>Cut size of meals</u>				
Yes	3	2	28	0.502
No	10	13		
<u>Not eat for whole day</u>				
Yes	4	3	28	0.512
No	9	12		
<u>Cut meals for children</u>				
Yes	3	2	28	0.502
No	10	13		

*, significant at $< .05$ level

APPENDIX C: SACS supervision model (SIP)

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S.A.C.S. A Structured Approach to Collaborative Supervision Charles (2016)

Minimum of 4 people

1) CASE PRESENTATION

a) Who is who?

Roles:

- **Facilitator (Fac):** Agrees contract/conditions; guides group; focusses discussion and suggestions; keeps time; monitors autonomy, respect and receptivity; may consult.
- **Case Presenter (CP):** Gives initial Q (no more than 10 words), outlines case with all important pieces of information; THE Q; chooses method.
- **CoSupervisors (CoS):** Listen (with whole self), self-reflexive and aware; comprehensive questions; offer clear and concise ideas/perspectives; work hard with chosen method; support the Fac.
- **Scribe (Sc):** The only one with pen and paper. Writes initial Q/THE Q; consulting mode; brief notes of suggestions to give to CP; may consult.

1b) How will we work together? (contract)

Agree on confidentiality, time management, clarity, respect, validity of everyone's opinion and openness (only needs to be done in detail periodically. Just check if anything new should be added at start of each session).

1c) What is the work?

CP starts with the question, which the Sc writes down and places on the table in the middle of the group. The CP then offers a 5-7 minute outline. During this stage no one else speaks. The Fac listens and guides (e.g. lets the presenter know when only 2 minutes left).

2) CASE CONSULTATION:

a) What is THE Question

The Fac again asks the CP for their key question (this may have changed slightly by this point) and the Sc writes it down.



The Fac asks if anyone in the group has any *clarifying questions*. There should only be a few of these. If there are many, this means the CP needs to give further information so the Fac then asks the CP if there is any more information they think the CoS need, and take them back to step 2.

2b) How should the group work with this Q?

The CP picks their method of feedback from the CoS, between the following:

- **Sounding board:** The CoS share what came up for them as they were listening to the CP (can include thoughts, feelings, physical sensations, urges, images, memories etc.).
- **Advice:** What the CoS think may be helpful to do in this situation (consider starting sentence with: "I", "My advice is/would be.....").

- 'Show me': Acting out the particular challenge the CP wants to work on. Each CoS 'role plays' the conversation with an empty chair, outside of the group:



- **Reflecting Team:** The CP moves out of the circle and turns his/her back towards the group and then the group (CoS) share their reflections about the case. This discussion should involve anything the CoS think is relevant to the key question.
- **Brainstorming:** Any ideas about how to move forward, no matter how random. These should be short statement, unfiltered and straight to the point.
- **Flip the question:** Changing the question round to the opposite and brainstorming around this.

2c) Group work to help the CP with their Q.

During this stage the CP does not speak and the CoS do not ask questions.
The consultation should always be conducted with the supervision question in mind.
 The Sc writes down all the points made by the CoS.

3) CASE CONCLUSION

a) Where do you go from here?

The Sc gives the CP the piece of paper with all the points made by the CoS and the CP shares their general feelings about the points made, picking up on the points that resonated the most. This should be done to the group as a whole, not to specific individuals within the group. The CP then focuses on the specific points that they will take forward.

3b) How did I do?

Feedback to the facilitator (only needs to be done from time to time if it is always the same facilitator).

3c) How did we do?

Finally, the group reflects on the process as a whole, with particular emphasis on the process and contract (no new 'ideas' at this point). This is also an opportunity for the CP to give feedback to the group.

APPENDIX D. Ethical approval (SIP)

1. University of Bath ethical approval

From: **psychology-ethics** psychology-ethics@bath.ac.uk
 Subject: RE: Ethics 17-210
 Date: 4 October 2017 at 10:15
 To: Cara Haines C.Haines@bath.ac.uk
 Cc: Cara Davis C.Davis@bath.ac.uk

P

Dear Cara,

Thank you for taking the time to make these amendments and clarifications. I am happy to confirm that you have full ethical approval for this amended application. Please use the code 17-210 as proof of ethical approval on all internal documentation.

It's an interesting point about consent being required for a questionnaire study. I have gone through the introduction you give and it seems to address the main points we require from a consent form. As the data will be anonymous it doesn't fall under the requirements of the data protection act. I will bring it up at the next committee meeting for discussion but am happy for you to proceed without written consent in this case.

In future please respond within the email chain, as instructed in the email and on the Psychology moodle page.

Best of luck with your research,
 Dr. Nathalia Gjersoe
 Chair, Psychology Ethics Committee

From: **Nathalia Gjersoe** N.Gjersoe@bath.ac.uk
 Subject: RE: 17-210: Amendment approved
 Date: 6 February 2018 at 09:29
 To: Cara Haines C.Haines@bath.ac.uk
 Cc: Cara Davis C.Davis@bath.ac.uk

NG

Dear Cara,

Thank you for letting us know about this amendment. I am happy to confirm that you have received full ethical approval, via Chair's Action. Your file will be updated to include these changes.

Best of luck with your research,
 Dr. Nathalia Gjersoe
 Chair, Psychology Ethics Committee

2. Great Western Hospital R&D confirmation

From: **TIMBRELLWHITTLE, Beatrice (GREAT WESTERN HOSPITALS NHS FOUNDATION TRUST)**
beatrice.timbrellwhittle@nhs.net
Subject: RE: R&D approval for small scale service evaluation
Date: 11 September 2017 at 14:54
To: CALLEBAUT, Leah (GREAT WESTERN HOSPITALS NHS FOUNDATION TRUST) leah.callebaut1@nhs.net
Cc: Cara Haines (C.Haines@bath.ac.uk) C.Haines@bath.ac.uk

BT

Dear Leah,

Many thanks for your email.

Good news – approval is not necessary for a Quality Improvement project at GWH.

However, do keep in touch as we often have celebratory events and we would love to have you involved at our next event.

Let me know if you need any further assistance,

Best Wishes

Bea

Beatrice Timbrell-Whittle
Quality Improvement Project Lead
Great Western Hospitals NHS Foundation Trust
Beatrice.TimbrellWhittle@gwh.nhs.uk
01793 60 (Ext:4737)



APPENDIX E. Adapted evaluation questionnaire (SIP)

(original available from British Psychological Society, 2015)

Please consider your experience of the supervision group over the last six months and rate each question using the scale below:

1	2	3	4	5
Not at all		Yes, definitely		

Question	Rating
I felt that this group is a safe space to reflect, ask questions, share my ideas and experiences	
I felt supported by other people in the group	
When I shared something with the group I felt heard by them	
I felt that other group members treated my contribution with respect when I shared something with them	
I have felt reassured that what I am doing as a professional to support cancer patients is good enough	
I feel that the way cases are discussed in this group is helpful for me	
By attending the group, I have considered how I look after myself	
I have regularly shared or addressed issues relevant to working with cancer patients	
I have come away from the group understanding a bit more about the experience and needs of a person with cancer	
As a result of attending the group I understand more about responding to patient distress	
I have learnt something useful about how to deal with challenging situations with my patients and their families	


Overall, how confident do you feel about discussing psychological problems with your patients with cancer?

10	9	8	7	6	5	4	3	2	1
Very confident					Not at all				

APPENDIX F. Ethical approval (MRP)

1. NHS Research Ethics Committee favourable opinion CFS clinic-recruited participants

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<p>Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval</p>	<div style="text-align: right;">  Health Research Authority South West - Frenchay Research Ethics Committee <small>Level 3, Block B Whitefriars Lewins Mead, Bristol BS1 2NT Email: nrescommittee.southwest-frenchay@nhs.net</small> </div>
<p>01 July 2016</p> <p>Dr Maria Loades University of Bath Claverton Down Bath BA2 7AY</p> <p>Dear Dr Loades</p> <p>Study title: Depression in Paediatric Chronic Fatigue Syndrome (CFS/ME) REC reference: 16/SW/0136 IRAS project ID: 203495</p> <p>Thank you for your submission of 29th June 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.</p> <p>The further information has been considered on behalf of the Committee by the Chair.</p> <p>We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss Natasha Bridgeman, nrescommittee.southwest-frenchay@nhs.net.</p> <p>Confirmation of ethical opinion</p> <p>On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.</p> <p>Conditions of the favourable opinion</p> <p>The REC favourable opinion is subject to the following conditions being met prior to the start of</p>	
<small>A Research Ethics Committee established by the Health Research Authority</small>	



Health Research Authority

the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see



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"Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [Cover Letter ref 203495]	1	14 April 2016
Covering letter on headed paper [Cover Letter ref 203495]	1	27 May 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Confirmation ref 203495]	1	12 April 2016
GP/consultant information sheets or letters [Info for healthcare professionals ref 203495]	1	12 April 2016
Interview schedules or topic guides for participants [Safety Plan Agreement Form]	1	12 April 2016
Interview schedules or topic guides for participants [K-SADS PL 5 2013]		
Interview schedules or topic guides for participants [Sections of KSADS used in study]		
Interview schedules or topic guides for participants [Sections of KSADS used in study]	2	27 May 2016
IRAS Application Form [IRAS_Form_20042016]		20 April 2016
IRAS Checklist XML [Checklist_29062016]		29 June 2016
Letters of invitation to participant [Consent to contact form ref 203495]	1	12 April 2016
Other [Debrief sheet]	1	12 April 2016
Participant consent form [Participant Consent Form 16+]	3	29 June 2016
Participant consent form [Participant Consent Form & 16s]	3	29 June 2016
Participant consent form [Participant Consent Form Parents]	3	29 June 2016
Participant information sheet (PIS) [Participant Information Sheet ref 203495]	3	24 June 2016
Research protocol or project proposal [Paediatric CFS & Depression study protocol]	3	24 June 2016
Summary CV for Chief Investigator (CI) [Maria's Brief CV]	1	12 April 2016
Summary CV for student [Rebecca Read (RA) CV]	1	03 June 2016
Summary CV for student [Sarah Stoll (RA) CV]	1	03 June 2016
Summary CV for student [Soraya S (RA) CV]	1	03 June 2016
Summary CV for supervisor (student research) [Esther Crawley CV ref 203495]	1	12 April 2016
Validated questionnaire [Clinical Assessment Pack]		
Validated questionnaire [Postal Questionnaire Pack for pre clinical assessment]		
Validated questionnaire [Postal assessment pack for over 12s - completed pre-clinical assessment]		
Validated questionnaire [RCADS Self-report]		
Validated questionnaire [RCADS Parent Report]		
Validated questionnaire [Brief Illness Perceptions Questionnaire]		
Validated questionnaire [Brief Illness Perceptions Questionnaire Parent Version]	2	27 May 2016



Health Research Authority

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at

<http://www.hra.nhs.uk/hra-training/>

**Health Research Authority****16/SW/0136****Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Mr Stephen Draper
Chair

Email: nrescommittee.southwest-frenchay@nhs.net

Enclosures: "After ethical review – guidance for
researchers"

Copy to: *Dr Birgit Whitman*
Jane Carter, Royal National Hospital for Rheumatic Diseases NHS
Foundation Trust

2. HRA approval CFS clinic-recruited participants

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Health Research Authority

Dr Maria Loades
University of Bath
Claverton Down
Bath
BA2 7AY

Email: hra.approval@nhs.net

08 August 2016

Dear Dr Loades,

Letter of HRA Approval

Study title:	Depression in Paediatric Chronic Fatigue Syndrome (CFS/ME)
IRAS project ID:	203495
REC reference:	16/SW/0136
Sponsor	University of Bristol

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

IRAS project ID	203495
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and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

IRAS project ID	203495
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HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **203495**. Please quote this on all correspondence.

Yours sincerely

Nicola Gilzeane
Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Birgit Whitman, University of Bristol, Sponsor Contact*
birgit.whitman@bristol.ac.uk

Jane Carter, Royal National Hospital for Rheumatic Diseases NHS Foundation Trust, Lead NHS R&D Contact
ruh-tr.RNHRDresearch@nhs.net

NIHR CRN Portfolio Applications Team
portfolio.applications@nihr.ac.uk

IRAS project ID	203495
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Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Covering letter on headed paper [Cover Letter ref 203495]	1	14 April 2016
Covering letter on headed paper [Cover Letter ref 203495]	1	27 May 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Bristol confirmation of insurance]		4 August 2016
GP/consultant information sheets or letters [Info for healthcare professionals ref 203495]	1	12 April 2016
Interview schedules or topic guides for participants [Safety Plan Agreement Form]	1	12 April 2016
Interview schedules or topic guides for participants [K-SADS PL 5 2013]		
Interview schedules or topic guides for participants [Sections of KSADS used in study]		
Interview schedules or topic guides for participants [Sections of KSADS used in study]	2	27 May 2016
IRAS Application Form [IRAS_Form_20042016]		20 April 2016
Letters of invitation to participant [Consent to contact form ref 203495]	1	12 April 2016
Other [Debrief sheet]	1	12 April 2016
Other [Schedule of Events]	2	27 July 2016
Other [Statement of Activities]	2	27 July 2016
Other [Notice of non-substantial amendment]		27 July 2016
Participant consent form [Under 16s]	4	27 July 2016
Participant consent form [Over 16s]	4	27 July 2016
Participant consent form [Parent]	4	27 July 2016
Participant information sheet (PIS) [PIS parent and child]	4	27 July 2016
Research protocol or project proposal [Paediatric CFS & Depression study protocol]	3	24 June 2016
Summary CV for Chief Investigator (CI) [Maria's Brief CV]	1	12 April 2016
Summary CV for student [Rebecca Read (RA) CV]	1	03 June 2016
Summary CV for student [Sarah Stoll (RA) CV]	1	03 June 2016
Summary CV for student [Soraya S (RA) CV]	1	03 June 2016
Summary CV for supervisor (student research) [Esther Crawley CV ref 203495]	1	12 April 2016
Validated questionnaire [Clinical Assessment Pack]		
Validated questionnaire [Postal Questionnaire Pack for pre clinical assessment]		
Validated questionnaire [Postal assessment pack for over 12s - completed pre-clinical assessment]		
Validated questionnaire [RCADS Self-report]		
Validated questionnaire [RCADS Parent Report]		
Validated questionnaire [Brief Illness Perceptions Questionnaire]		
Validated questionnaire [Brief Illness Perceptions Questionnaire Parent Version]	2	27 May 2016

IRAS project ID	203495
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Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Birgit Whitman (0117 331 7130, birgit.whitman@bristol.ac.uk)

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	A non-substantial amendment was submitted following REC approval to update consent documentation to bring it in line with HRA standards
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	A statement of activities has been submitted to act as agreement between the sponsor and NHS organisations to participate.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional

IRAS project ID	203495
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Section	HRA Assessment Criteria	Compliant with Standards	Comments
			indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	The statement of activities confirms no funding will be provided by the sponsor to sites. The applicant has confirmed that an application for funding from the NIHR for doctoral fellowship is in progress. The applicant has confirmed that the study will proceed even if the funding application is not secured.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

IRAS project ID	203495
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Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type for this study; all sites will undertake the same activities.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A local collaborator would be expected at sites where access for external staff may need to be facilitated.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

IRAS project ID	203495
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HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

Letters of Access will be expected if any external staff, without an existing contractual relationship in place, will access the site. Sites to confirm the necessary DBS and Occupational Health checks have been completed.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

3. University of Bath approval CFS clinic-recruited participants

Page 1/1

<p>Dr Michael J Proulx Chair, Psychology Ethics Committee Telephone +44 01225 385963 Facsimile +44 01225 386752 E-mail: psychology-ethics@bath.ac.uk</p>	<p> UNIVERSITY OF BATH Department of Psychology Bath BA2 7AY · United Kingdom</p>
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18th July 2016

Dear Dr. Maria Loades

Reference number 16-203: Depression in Paediatric Chronic Fatigue Syndrome

I am writing to confirm that the Psychology Ethics Committee has provided full ethical approval for the above project, as decided by Dr Ailsa Russell via Chair's Action.

Best wishes with your research.



Dr Michael J Proulx
Chair Psychology Ethics Committee

4. NHS Research Ethics Committee favourable opinion JIA and T1D clinic-recruited participants

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Gwasanaeth Moeseg Ymchwil
Research Ethics Service



Wales REC 3
Health and Care Research Wales Castlebridge 4
15 – 19 Cowbridge Road East
Cardiff CF11 9AB
Telephone : 029 2078 5735

E-mail : corinne.scott@wales.nhs.uk
Website : www.hra.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

27 January 2017

Miss Cara Haines
Trainee Clinical Psychologist
Taunton and Somerset NHS Foundation Trust
10W, Department of Psychology
University of Bath
Claverton
Bath BA2 7AY

Dear Miss Haines

Study title:	Illness perceptions in young people with long term conditions
REC reference:	16/WA/0378
Protocol number:	N/A
IRAS project ID:	212752

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by a Sub-Committee of the REC at a meeting held on 27 January 2017. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm

through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover letter outlining amendments]	Version 1	08 January 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance documents]	2	10 October 2016
IRAS Application Form [IRAS_Form_10112016]		10 November 2016
IRAS Checklist XML [Checklist_10112016]		10 November 2016
IRAS Checklist XML [Checklist_08012017]		08 January 2017
IRAS Checklist XML [Checklist_11012017]		11 January 2017
Letter from sponsor [Sponsorship Approval]	1	09 November 2016
Other [Schedule of events]		18 November 2016
Other [Statement of Activities]		18 November 2016
Other [Participant debrief sheet]	Version 2	07 January 2017
Other [Assent question screenshot]	Version 1	07 January 2017
Participant consent form [Participant/parent/carer consent (online)]	V1	19 September 2016

Participant information sheet (PIS) [Parent/carer info sheet for 11-15 year olds (online)]	V1	19 September 2016
Participant information sheet (PIS) [Amended PIS age 16-17]	Version 2 (without track changes)	07 January 2017
Participant information sheet (PIS) [PIS 11-15 print version]	V2	07 January 2017
Participant information sheet (PIS) [PIS 16-17 track changes]	V2	07 January 2017
Participant information sheet (PIS) [PIS 11-15 track changes print version]	V2	07 January 2017
Research protocol or project proposal [Amended protocol/proposal]	Version 2 (with track changes)	08 January 2017
Summary CV for Chief Investigator (CI) [Cara brief CV]	1	18 September 2016
Summary CV for student [Madeline CV]	1	18 September 2016
Summary CV for supervisor (student research) [Maria brief CV]	1	18 September 2016
Summary CV for supervisor (student research) [Cara Davis CV]	1	18 September 2016
Validated questionnaire [BIPQ]	V1	19 September 2016
Validated questionnaire [RCADS]	V1	19 September 2016
Validated questionnaire [chalker fatigue scale (CFQ)]	V1	19 September 2016
Validated questionnaire [SF-36 physical functioning subscale]	V1	19 September 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/WA/0378

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



Dr. Corinne Scott
Senior Ethics Service Manager
Health and Care Research Wales

pp **Mrs. Monika Hare**
Vice Chair

E-mail: corinne.scott@wales.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting
 and those who submitted written comments
 "After ethical review – guidance for researchers"

Copy to: Professor Jonathan Knight
 Rachel Brophy, University Hospitals Bristol NHS Foundation Trust

Wales REC 3

Attendance at Sub-Committee of the REC meeting on 27 January 2017

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Monika Hare	Vice Chair / Lay member	Yes	Chaired meeting
Dr Richard Walker	Alternate Vice Chair / Lay Plus member	Yes	
Mr Stewart Williams	Lay Plus member	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr Corinne Scott	Senior Ethics Service Manager



Gwasanaeth Moeseg Ymchwil
Research Ethics Service



Wales REC 3

Health and Care Research Wales Support Centre
Castlebridge 4
15-19 Cowbridge Road East
Cardiff CF11 9AB

Telephone : 029 2078 5741
E-mail : helen.williams19@wales.nhs.uk
Website : www.hra.nhs.uk

29 August 2017

Miss Cara Haines
Trainee Clinical Psychologist
Taunton and Somerset NHS Foundation Trust
10W, Department of Psychology
University of Bath
Claverton, Bath
BA2 7AY

Dear Miss Haines

Study title:	Illness perceptions in young people with long term conditions
REC reference:	16/WA/0378
Protocol number:	N/A
Amendment number:	1
Amendment date:	20 August 2017
IRAS project ID:	212752

Thank you for submitting the above amendment, which was received on 24 August 2017. I can confirm that this is a valid notice of a substantial amendment and will be reviewed by the Committee at its next meeting on 14 September 2017.

Documents received

The documents to be reviewed are as follows:

Document	Version	Date
Covering letter on headed paper	Signed by Cara Haines	18 August 2017
Notice of Substantial Amendment (non-CTIMP)	1	20 August 2017
Research protocol or project proposal	3 (tracked changes)	25 August 2017
Research protocol or project proposal	3 (clean)	25 August 2017

The Committee will issue an ethical opinion on the amendment within a maximum of 35 days from the date of receipt.

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval for the research.

We are pleased to welcome researchers and R & D staff at our Research Ethics Service Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/WA/0378:

Please quote this number on all correspondence

Yours sincerely



Mrs Helen Williams
Health and Care Research Wales
Research Ethics Committee Co-ordinator

Email - helen.williams19@wales.nhs.uk

Copy to: Rachel Brophy, University Hospitals Bristol NHS Foundation Trust
Professor Jonathan Knight

5. HRA approval JIA and T1D clinic-recruited participants

Page 1/8



Health Research Authority

Miss Cara Haines
 Trainee Clinical Psychologist
 Taunton and Somerset NHS Foundation Trust
 10W, Department of Psychology
 University of Bath
 Claverton, Bath
 BA2 7AY

Email: hra.approval@nhs.net

08 February 2017

Dear Miss Haines

Letter of HRA Approval

Study title:	Illness perceptions in young people with long term conditions
IRAS project ID:	212752
Protocol number:	N/A
REC reference:	16/WA/0378
Sponsor	University of Bath

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

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Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	212752
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It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

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Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

IRAS project ID	212752
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User Feedback

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HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **212752**. Please quote this on all correspondence.

Yours sincerely

Thomas Fairman
HRA Assessor

Email: hra.approval@nhs.net

Copy to: *Professor Jonathan Knight, University of Bath, (Sponsor Contact)*
Ms Rachel Brophy, University Hospitals Bristol NHS Foundation Trust,
(Lead NHS R&D Contact)

IRAS project ID	212752
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Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

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Other [Statement of Activities]	1	08 February 2017
Other [Participant debrief sheet]	Version 2	07 January 2017
Other [Assent question screenshot]	Version 1	07 January 2017
Other [Sponsor Confirmation of non-substantial amendments]		23 February 2017
Participant consent form [9_2_17 consent form]	2	09 February 2017
Participant information sheet (PIS) [9_2_17 PIS 16to17]	3	09 February 2017
Participant information sheet (PIS) [9_2_17 PIS 11to15]	3	09 February 2017
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IRAS project ID	212752
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Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Professor Jonathan Knight

Tel: 01225383162

Email: pro-vc-research@bath.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	<p>The sponsor has submitted the HRA Statement of Activities and intends for this to form the agreement between the sponsor and study sites.</p> <p>The sponsor is not requesting, and does not require any additional contracts with study sites.</p>
4.2	Insurance/indemnity	Yes	Where applicable, independent contractors (e.g. General Practitioners)

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Section	HRA Assessment Criteria	Compliant with Standards	Comments
	arrangements assessed		should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No application for external funding has been made.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion was issued by the Wales Research Ethics Committee 3 on the 27 th January 2017. Amended documents were submitted on by the researchers to comply with HRA Approval standards. These were classified by the sponsor as a non-substantial amendment.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether

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the activities at all organisations are the same or different.

All participating NHS organisations will undertake the same study activities. There is therefore only one study site 'type' involved in the research.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

NHS organisations in England that are participating in the study **will be expected to formally confirm their capacity and capability** to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Local Collaborator should be appointed at study sites.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

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If members of the external research team will be attending NHS sites to conduct the study activities detailed at IRAS SA18 and A19 they should obtain a Letter of Access. This would be on the basis of a Research Passport or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). Pre-engagement checks should confirm standard DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

6. University of Bath approval JIA and T1D clinic-recruited participants

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From: **psychology-ethics** psychology-ethics@bath.ac.uk
Subject: Ethics 17-019
Date: 10 February 2017 at 18:25
To: Cara Haines C.Haines@bath.ac.uk



Dear Cara,

Thank you very much for completing the application and including the relevant documents. Following approval from the NHS REC panel, I am happy to confirm that you have full ethical approval from Bath University via Chair's Action. Please use the code 17-019 as your ethics code for any internal requirements.

Best of luck with your data collection,

Dr. Nathalia Gjersoe
Chair, Psychology Ethics Committee

From: Cara Haines
Sent: 10 February 2017 13:01
To: Nathalia Gjersoe <N.Gjersoe@bath.ac.uk>
Subject: Ethical approval

Dear Nathalia,

Please find attached my application for University ethical approval for my main research project, to be reviewed via chair's action.

I have attached the letter of favourable opinion from the NHS REC panel that reviewed it, as well as the Participant Information Sheets, consent form, debrief sheet and questionnaires.

Please let me know if you require any more information.

Best wishes,

Cara Haines
Trainee Clinical Psychologist
University of Bath
C.Haines@bath.ac.uk

7. University of Bath approval online-recruited participants

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From: **psychology-ethics** psychology-ethics@bath.ac.uk
 Subject: RE: Amendment request 17-019.
 Date: 26 July 2017 at 10:02
 To: Cara Haines C.Haines@bath.ac.uk, psychology-ethics psychology-ethics@bath.ac.uk



Dear Cara,

Thank you for letting us know about this amendment. I am happy to confirm that you have received full ethical approval, via Chair's Action. Your file will be updated to include these changes. Please be aware that university specifications for safe storage of personal human data require that data files be kept encrypted as well as password protected (in this instance the consent forms). Please be aware of these specifications and implement in your data storage plan: <http://www.bath.ac.uk/data-protection/guidance/academic-research/index.html>

Best of luck with your research,
 Dr. Nathalia Gjersoe
 Chair, Psychology Ethics Committee

From: Cara Haines
Sent: 24 July 2017 11:14
To: psychology-ethics <psychology-ethics@bath.ac.uk>
Cc: Nathalia Gjersoe <N.Gjersoe@bath.ac.uk>
Subject: Amendment request 17-019.

FAO: Chair's Action

My project has already been approved by the University of Bath (ethics code 17-019) and has full NHS ethical approval. I would like to request an amendment in order to additionally recruit non-NHS participants online. This amendment is therefore being requested from the University of Bath ethics board only, and not NHS ethics. From my understanding of the online guidance, this can be considered under the Chair's Action. Please let me know if this is not the case.

Due to my project having been granted NHS ethics, my previous University of Bath ethics application did not contain answers for questions 2-18. Please find attached a more detailed ethical application form. I have highlighted in yellow the specific amendments being requested.

Very best wishes,
Cara Haines
 Trainee Clinical Psychologist
 University of Bath
C.Haines@bath.ac.uk

APPENDIX G. Statistical power calculations (MRP)

Although Moss-Morris and Chalder (2003) compared illness perceptions between individuals with CFS and rheumatoid arthritis, they used the IPQ-R rather than the BIPQ, meaning effect sizes are unlikely to be directly comparable.

The brief-IPQ was used in a recent study comparing illness perceptions in CFS patients and non-CFS fatigued patients (De Gucht et al., 2016). Significant between-group differences were found on four variables. Sample size required to detect these differences are outlined in Table 5, based on the data reported in the study. With equal sample sizes, a sample of 37 in each group would be large enough to detect differences on $\frac{3}{4}$ of the variables.

Table 5. Required sample size to detect effects based on data from De Gucht et al. (2016).

Significant variables	Non-CFS mean (N=192)	CFS mean (N=192)	Non-CFS SD	CFS SD	Sample size required for each group (equal sizes)	Overall sample size N2/N1 = 3
Consequence	6.93	8.5	1.73	1.57	37	98
Timeline	5.39	7.57	1.99	1.95	28	74
Treatment control	3.44	4.47	2.56	2.58	195	520
Identity	5.33	7.41	2.24	2.08	36	94

Power set to 0.8; two-tailed; alpha Bonferroni adjusted to 0.002 for multiple comparisons

APPENDIX H. Supplementary analysis (MRP)

Analysis of illness perceptions in depressed vs non-depressed participants

Background

CFS has a high comorbidity with depression; it is estimated that 29% of young people with CFS also have depression and this is associated with disease severity (Bould, Collin, Lewis, Rimes, & Crawley, 2013). Beck's (1979) cognitive theory of depression outlines that depressed individuals have negatively biased cognitions, which maintains the depression. According to the CSM, such negative cognitions may form part of an individual's psychological context, which feeds into the cognitive perceptions held about illness, as well as the coping strategies utilised (Leventhal, Weinman, Leventhal, & Phillips, 2008). The CSM also proposes that emotional reactions to illness (including feelings of depression) are processed in parallel to cognitive perceptions (Diefenbach & Leventhal, 1996); these emotional perceptions influence coping and outcomes, which in turn feed back into cognitive perceptions. In line with this, depression in adults has been associated with more negative illness perceptions in a number of physical health conditions (Grace et al., 2005; Murphy, Dickens, Creed, & Bernstein, 1999; Philip, Lindner, & Lederman, 2009). To date, no studies have looked at the relationship between depression and illness perceptions in young people with CFS.

Method

Gender, grade and raw scores for RCADS depression subscale can be used to generate t-scores (Chorpita, Ebesutani, & Spence, 2015). A t-score of ≥ 70 indicates clinical threshold for 'probable depression' has been met and was used to divide participants into 'depressed' and 'non-depressed' subgroups. Participant age was used to infer grade. To compare depressed and non-depressed participants, a series of Mann-Whitney tests were conducted using BIPQ subscales as the dependent variable and binary depression variable (depressed vs. non-depressed) as the independent variable. Holm-Bonferroni correction was used for multiple comparisons.

Results

Comparisons found that depressed participants' ratings were significantly higher on consequences, identity and emotional response subscales compared with non-depressed participants. Depressed participants rated their personal control significantly lower than non-depressed participants. See Table 6.

Table 6. Comparison of depressed and non-depressed participants in BIPQ subscales

	Depressed <i>N</i> = 43 CFS=19; JIA=9; T1D=15	Non-depressed <i>N</i> = 87 CFS=17; JIA=33; T1D=37	<i>p</i> value
	<i>M (SD)</i>	<i>M (SD)</i>	
Consequences	7.44 (1.76)	6.03 (2.12)	<.001*
Timeline	7.98 (2.35)	7.78 (2.48)	.682
Personal control	3.60 (2.35)	4.84 (2.29)	.007*
Treatment control	6.12 (2.79)	7.33 (2.36)	.018
Identity	7.02 (2.25)	5.91 (2.14)	.001*
Concern	6.28 (2.89)	5.31 (2.39)	.032
Understanding	7.26 (2.53)	7.82 (2.03)	.304
Emotional response	7.70 (1.97)	5.62 (2.85)	<.001*

*significant using Holm-Bonferroni adjust *p*-values